Moral economies of kidney disease and care: Interdependencies between Yolŋu and the Australian state

Stefanie Puszka

October 2021

A thesis submitted for the degree of Doctor of Philosophy of
The Australian National University

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university. To the best of the author's knowledge, it contains no material previously published or written by another person, except where due reference is made in the text. This thesis comprises approximately 92, 625 words.

Stefanie Puszka

October 2021

Acknowledgements

Dedicated to the memory of the late Mr Muŋuḻpurr Bruce Gutiwa Dhamarrandji.
Marrŋal ŋarra dhuwal, ga bulu ŋarra dhuwal dhayinhu, dhabanba.

This thesis would not have been possible without the contributions of knowledge, advice, brokerage and of care of the late Mr Muŋuḻpurr and of Yinin Dhurrkay. Mr Muŋuḻpurr, who I came to call *mäḻu* (father), and Yinin, who I came to call *dhuway* (cousin or sister-in-law), worked with me as Yolŋu co-researchers. They were my teachers, collaborators, advocates, and often my passports in Yolŋu and Balanda worlds. Thank you, *mäḻu* and *dhuway.*

I owe a great debt to all the Yolŋu interlocutors involved in this project who shared their stories of hardship and deprivation with me, as well as their stories of strength and survival. I hope I have done your words, knowledge and experiences justice.

I also owe thanks to all of the many service providers and policymakers who participated in interviews and helped facilitate my research in renal services.

In undertaking this project, I took up an opportunity to undertake doctoral studies at the Centre for Aboriginal Economic Policy Research at the Australian National University and at Menzies School of Health Research at Charles Darwin University through a joint PhD program between the two institutions. My dual institutional affiliations and my thesis topic itself required a large supervision panel. I could not have hoped for a more attentive, helpful and caring primary supervisor than Katie Curchin, who was a source of constant advice and support throughout my entire candidature. Katie assisted me to navigate countless fieldwork, theoretical, institutional and practical quandaries and generally commented on draft work rapidly. Thanks to Katie, the quality of my writing improved considerably over the course of my studies. Katie supported a number of side-projects I undertook, as well as grant applications, papers and reports I wrote. Katie checked on my wellbeing at difficult times including following the deaths of several Yolŋu interlocutors even visited me in Darwin during fieldwork.

Julie Lahn joined my supervision panel when a change in affiliations within the panel necessitated acquiring another supervisor based at CAEPR. Julie took on the role of chair of my supervision panel

and ensured that I met the administrative requirements of my candidature. Julie provided helpful comments on drafts, with an eye to positioning and style. Conversations with Julie about my thesis were always rewarding and reassuring.

Paul Lawton was a source of content expertise on end stage kidney disease among Indigenous populations and on renal services and gladly shared this knowledge with Yinin, Mr Muŋuḻpurr and I. His passion for improving the lot of Indigenous renal patients and expanding access to dialysis on country was inspiring. Paul was also a source of more general advice on handling the difficulties of PhD life. Many conversations with Paul helped me to refine my thesis.

Alan Cass contributed considerable knowledge of the policy context of renal services. He connected me to policymakers and stakeholders in Darwin and Canberra though his vast professional networks. Alan provided guidance on the shape of my original thesis proposal, reviewed funding applications with tight deadlines and even attended my thesis proposal review in Canberra.

Francesca Merlan and Carly Schuster provided insightful comments at key moments and welcome guidance on the shape of the thesis and on approaching fieldwork. I am indebted to Francesca for sharing her weighty scholarly expertise by reading several drafts.

Beyond my supervision panel, I have benefited from comments provided on draft chapters and papers by many research students and faculty members: Yasmine Musharbash, Julia Brown, Francis Markham, Bill Fogarty, Alex D'Aloia, Patrick Guinness, Hanna Jagtenberg, Frances Morphy, Danielle Aquino, Mascha Friderichs, the ANU School of Anthropology and Archaeology Thesis Writing Group and the Menzies/CDU Qualitative Writing Group. I am grateful to the people who engaged in conversations with me about my work that assisted my thinking. Conversations with Jeannie Devitt, Bettina Cass, Jamie Mapleson, Patj Patj Janama Robert Mills, Anne Lowell, Beau Austin, Gill Gorham, Howard Amery, within the Yolŋu Studies program at CDU and among the Yolŋu studies conversation group members all helped to develop this thesis.

Completing a thesis is a long, difficult and consuming process. I am thankful to those who shared PhD rites of passage with me, as well as their friendship, laughter, insights and support: Josie Povey, Kylie Wong Dolan, Nina Nichols, Danielle Aquino, Simone Georg, Talia Avrhamazon, Kaely Woods, Tess McGirr, Carolin Stock, Rifka Sibarani, Kat Tuite, Vicki Kerrigan, Rebecca Amery, Alex D'Aloia and the ANU Anthropology PhD cohort of 2017.

Sally Wotha, May Garrawirtja, Chantelle Dhamarrandji, Amanda Dhamarrandji, Recheanda Marika and Farrah Dhamarrandji opened their doors to me and cared for me in Galiwin'ku. Renee de Jong, Julie Lahn, Megan Whitty and Kylie Wong Dolan shared their homes in Canberra with me. Carlee and Josh Mark provided a place to stay and access to a car in Nhulunbuy, in addition to connecting me with local health service providers and providing me with medical care when I was sick.

Tricia Nagel and the mental health research team at Menzies enabled me to continue working in my pre-candidature job at reduced hours and while studying in Canberra. They were always supportive of my research and understanding of the demands of PhD life.

Billy Lynch, my partner in life, shared much of this journey with me. From allowing me to monopolise his car during fieldwork, to being drawn into the lives of Mr Muŋulpurr's extended family, to visiting me while I was in Canberra, to taking over much of the household labour while I finished my thesis, Billy was there. Thank you for sharing the excitements, disappointments, successes, sorrows and frustrations with me.

My family, Susy, Michael, Leon and Helena Puszka, although physically distant, were always supportive and encouraging from afar.

This work was funded by a National Health and Medical Research Council postgraduate scholarship (APP113270); a National Health and Medical Research Council project grant (APP1092092); a Barbara Hale Fellowship from the Australian Federation of Graduate Women; a write-up scholarship provided by Menzies School of Health Research; and fieldwork funds provided by the Centre for Aboriginal Economic Policy Research and by Menzies School of Health Research. A Jeff Cheverton Memorial Scholarship funded by Brisbane North Primary Health Network and North Western Melbourne Primary Health Network enabled me to undertake an internship program with the Australian Healthcare and Hospitals Association and develop a policy brief connected to this thesis.

Abstract

My thesis analyses the social, economic and political relations of care that arise through end stage kidney disease in an Australian Indigenous society. An epidemic of end stage kidney disease amongst Indigenous Australians, and poor access to life-sustaining dialysis treatment in remote communities, sees healthcare for patients from remote areas administered through urban displacement. I consider how the care for Yolŋu renal patients is practiced and valued in Yolŋu families and in health and social policy. I explore how the multiple values and practices of care for Yolŋu renal patients in Yolŋu families and in health and social policy interact; and the implications for relations between Yolŋu and the state. In this thesis I bring together the scholarship of care, the anthropology of Indigenous economy and classic gift theory in a novel way. I adopt an ethnographic approach grounded in renal patients' and carers' narratives, while also incorporating service provider and policymaker perspectives.

I begin by exploring the social suffering produced by kidney disease and the relations and practices of domestic care in the families of Yolŋu renal patients, describing a Yolŋu ethics of care. I show that care-giving is understood by Yolŋu as investing value in people, relationships, family solidarity and material equality. Giving and receiving care is understood by Yolŋu primarily as a relationship between generations, and may provide a means of exercising power and responsibility within gendered and age-based social roles. Care is enacted through interlocking material and non-material reciprocities in Yolŋu domestic moral economies.

I go on to explore how Yolŋu attempt to realise a Yolŋu ethics of care through healthcare, social housing and social security payments. I show that while some of the care needs of renal patients are recognised in health and social policy, the everyday subsistence struggles of their carers and other kin are often neglected in public policy embodying neoliberal values of self care, self sufficiency and responsibilisation. My research reveals how the neoliberal state relies on social relations and care practices in Yolŋu families, constituted through fundamentally different values, to realise health and social policy agendas. Yolŋu care practices such as performing domestic labour rather than working in the formal economy, sharing, extending shelter to kin, and hunting and gathering are mobilised yet marginalised by the neoliberal state. Neoliberal values of care are parasitic on social roles within families and in some cases may strain relations among kin, reproducing bodily, social and economic precarity.

By considering the intertwining of material and non-material dimensions of care, my thesis challenges received ideas about Indigenous dependency on state welfare. I show that an interdependent but unequal relationship exists between Yolŋu families and the state, through health and social policy agendas, in satisfying the basic needs of life of Yolŋu renal patients and their kin. Such interdependencies become particularly salient in times of post-universal, conditional healthcare and welfare. In some circumstances, they also provide a means by which Yolŋu may exercise power and gain recognition from the state.

A note on languages and pronunciation

Interviews and conversations with Yolŋu interlocutors were conducted in English, Djambarrpuyŋu and occasionally other Yolŋu languages. Frequently they involved a mix of English and Yolŋu matha (Yolŋu languages). When quoting interlocutors who were predominantly speaking in English, interspersed with some words spoken in Yolŋu matha, I have maintained the Yolŋu matha and have included English translations in brackets in order to preserve something of the original quality of these statements. Where interlocutors used many Yolŋu matha words within individual sentences, or spoke entirely or predominantly in Yolŋu matha, I have translated entire statements into English in order to render them readable.

Conventions regarding the representation of Yolŋu matha in text established by the Yolŋu Studies program at Charles Darwin University are adopted in this thesis (Christie & Gaykamaŋu 2004). The letter *ŋ* in the Yolŋu alphabet denotes the sound *ng*, as in the English term *sing*, and a different sound to the *ng* in the English word *angle*. Yolŋu matha terms often feature the letters *ny* together. This denotes a sound that does not occur frequently in English, however the *y* component of *ny* sounds similar to the *y* sound in the English term *yellow.* This sound is different to the *y* sound in the English term *many*. In Yolŋu matha the letter *ä* denotes a long *a* as in the English word 'father'. Underlined letters (eg: *l̲, n̲, d̲)* sound similar to their English equivalents but are retroflexed, or pronounced with the tip of the tongue curled back within the mouth. In Yolŋu matha, *'rr'* represents a rolled-r sound.

In translating Yolŋu matha to English, for short and straightforward text I used an online dictionary compiled by Charles Darwin University researchers and their many Yolŋu collaborators (Charles Darwin University 2014). Longer and more complicated text was translated by Yolŋu co-researchers. Of the Yolŋu co-researchers I worked with, Yinin is an experienced Yolŋu language consultant and the late Mr Muŋul̲purr was a Djambarrpuyŋu traditional owner.

Table of Contents

List of Tables

List of Figures

Introduction

Conceptualising the problem of care for Yolŋu renal patients

I took a deep breath, straightened my skirt and hoped that this would go well. It was 2016 and I was about to embark on my first visit to the Nightcliff Renal Unit, located in a suburb of Darwin, the capital of Australia's Northern Territory. My job at the time, at Menzies School of Health Research, required me to consult with the Unit's manager about a new research project addressing the wellbeing of Indigenous renal patients. I was given a tour of the facility before discussing the project with the manager in her office. Patients, tightly packed, were seated in large vinyl armchairs besides dialysis machines while their blood circulated between their arms and the machines via transparent tubes. Non-Indigenous patients were evidently the exception in the Unit, and one man I was introduced to explained that he had left his kin and country and was unable to return to them due to the demands of his treatment. What struck me the most, however, were several patients I recognised. They were members of a group of rough sleepers who I had noticed hanging out their blankets on fences along the Nightcliff foreshore each morning over the previous weeks on my daily commute to work. I began to contemplate the disjunctures and ambivalences of care that enabled healthcare systems to offer patients life-sustaining treatment three times a week while displacing them from their families and communities and rendering them homeless; how in an affluent state such as Australia, one kind of suffering had acquired legibility in public policy, while other basic needs of life of these patients had not.

In public policy, care is often conceptualised as necessary but burdensome, as a labour or service dispensed to patients, citizens and family members through unidirectional relationships of dependency. In health policy care is often conflated with treatment and constructed as a burden to society, families and patients themselves. The concept of 'burden of disease' is imbued with the weight of care understood as a problem of dependency and a drain on public funds and individual productivity (Macdonald et al. 2019). Conceptualisations of care as a relation that creates dependency

are intrinsic to social policy, in which welfare programs that alleviate poverty are generally subject to substantial means-testing and measures that attempt to compel forms of mutual obligation amongst beneficiaries (Power & Mee 2019; Thelen 2015). In the Australian Government's Closing the Gap meta-framework of Indigenous health policy, care serves as a necessary instrument for achieving statistical biomedical health equality between Indigenous and non-Indigenous Australians and equality in other social indicators (Australian Government 2020). Achieving statistical biomedical health equality is conceptualised as a measure of reparation fundamental to the Australian state's responsibilities to Indigenous citizens; and as a means for the state to assuage historic debts of colonisation, legitimising the expenditure of public funds on healthcare (Altman 2009a; Kowal 2015). In public policy and at the Nightcliff Renal Unit, care is overwhelmingly conceptualised as a gift that creates or assuages social debts and as a gift that is in some circumstances necessary, but one that can lead to dependency. In public policy and at the Nightcliff Renal Unit, relational dimensions of care beyond unidirectional dependency are neglected.

My thesis considers the social, economic and political relations of care that arise through end stage kidney disease in an Australian Indigenous society. It is a product of the eventual research project that emerged from my first visit to the Nightcliff Renal Unit. It is a markedly different project from the one I set out to discuss on that particular day and has required me to listen deeply to patients' stories of suffering and of care. I consider how care for Yolŋu renal patients is enacted as a relation in families, in renal services and between Yolŋu citizens and the Australian state beyond unidirectional relationships of dependency. I consider how the care for Yolŋu renal patients is practiced and valued in Yolŋu families and in health and social policy. I explore how the multiple values and practices of care for Yolŋu renal patients in Yolŋu families and in health and social policy interact; and the implications for relations between Yolŋu and the state. I adopt an ethnographic approach grounded in renal patients' and carers' narratives, while also incorporating service provider and policymaker perspectives.

In this thesis I adopt an analytical approach to care that is attentive to care as a social, economic and political relation. I understand care as constituted through interpersonal relationships and structural conditions (Smith-Morris 2018). In this thesis, care encompasses physical labour, bodies of knowledge, affective dispositions and entitlements and obligations. As a polysemic concept, care traverses boundaries between the public and private, affective and material, embodied and expert knowledge, human and machine (Lock & Gordon 1988; Milligan, C 2003; Thelen 2015). Oppositions held to exist between 'warm', affective, familiar domestic care and 'cold', utilitarian, rational healthcare have long been dissolved by care scholarship within the social sciences (Andaya 2009; Hochschild 1983; Mol et al. 2010; Zelizer, V A 2009) and are not maintained in this thesis. Following Lisa Stevenson (2014),

ultimately, I conceptualise care as a value that seeks to explain our responsibilities to others and to ourselves.

In the following sections I further explore the problem of care for Yolŋu renal patients, discussing end stage kidney disease amongst Indigenous people in the Northern Territory and poor access to treatment in remote areas; the political economy of the Northern Territory, in which renal services are embedded; and historic and contemporary relations between Yolŋu and the Australian state. After describing the problem of care for renal patients, I review approaches to care in international social science scholarship and the ways in which care and social value have been conceptualised in the anthropology of Australian Indigenous economies. Finally, I describe my conceptualisation of the problem of care for Yolŋu renal patients.

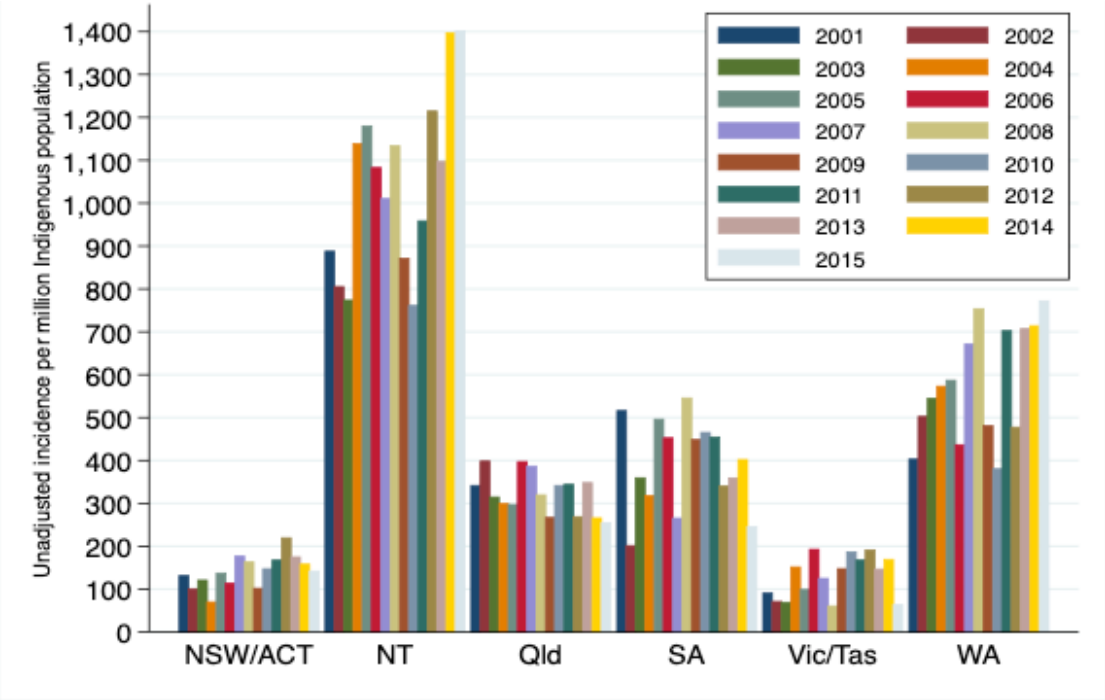
End stage kidney disease in the Northern Territory: a problem of care

Kidney disease amongst Indigenous Australians

In a biomedical explanatory model, loss of kidney function reduces the body's capacity to filter waste, produce hormones and vitamins and regulate blood pressure (Stumpers & Thomson 2013). Kidney disease is defined as kidney damage or reduced kidney function sustained for 3 months or more (Australian Institute of Health and Welfare 2019). End stage kidney disease occurs when renal replacement therapy is required to sustain life (Stumpers & Thomson 2013). Like many chronic diseases, kidney disease can be described as a manifestation of structural inequalities, associated with low birth weight, lifelong nutrition and chronic infectious disease (Cass, A et al. 2004).

Kidney disease disproportionately impacts Indigenous people in Australia and internationally (Australia and New Zealand Dialysis and Transplant Registry 2018; Wilson et al. 1994). Kidney disease impacts Indigenous Australians at substantially earlier ages compared to non-Indigenous populations (Australian Health Ministers' Advisory Council 2015), and in remote Australia, rates of end stage kidney disease amongst Indigenous people are 15 or more times higher than amongst non-Indigenous Australians of the same age and sex (Australia and New Zealand Dialysis and Transplant Registry 2016; Cass, A et al. 2001). The high and rapidly increasing incidence of end stage kidney disease amongst Indigenous Australians is most marked in the Northern Territory, where it is predicted that the patient cohort will surpass 1000 people by 2022 (You et al. 2017; Figure 1).

Figure 1 Incidence of renal replacement therapy for Indigenous Australians 2001 - 2015 by state



Credit: Lawton (2017)

Amongst Indigenous People in the Northern Territory, high rates of end stage kidney disease are a relatively recent phenomenon. While few cases were reported prior to the 1980s, the incidence of end stage kidney disease has been increasing rapidly since the mid-1990s (Gorham et al. 2018). Although Indigenous People comprise around 30% of the population of the Northern Territory, they comprise around 85% of the Northern Territory's renal patients (Gorham et al. 2018). High rates of end stage kidney disease amongst Indigenous Australians in recent times are associated with the rapid transition to Western diets, more sedentary lifestyles and crowded housing conditions (Cass, A et al. 2004).

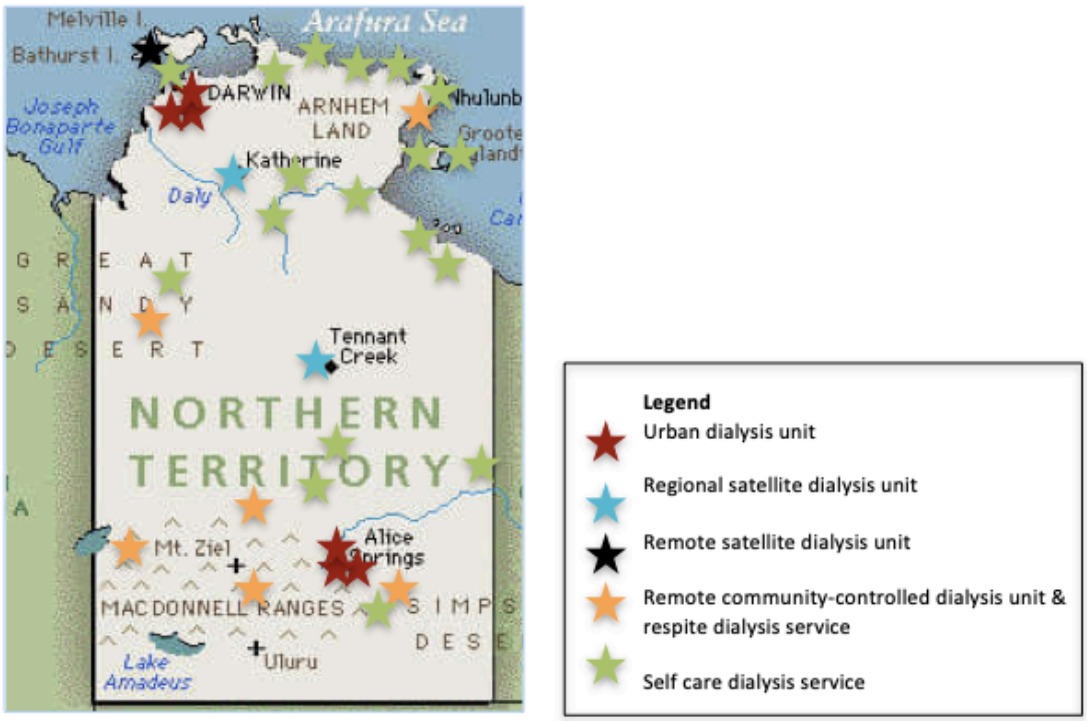
Yolŋu report that the illnesses understood as chronic diseases in biomedical explanatory models were unknown prior to colonisation, as Chapter Two and Eight will explore. As I will discuss, in Yolŋu conceptualisations of health, states of health and illness figure as physical and social states, animated by the experiences of bodily sensations, emotions, thoughts, impulses and sensory perceptions. Aspects of the biomedical model converged with renal patients' experiences of kidney disease and could be assimilated into their own explanatory models.

Access to biomedical treatment for end stage kidney disease in the Northern Territory

Biomedical treatment for end stage kidney disease, known as renal replacement therapy, comprises either kidney transplantation or ongoing dialysis treatment. While kidney transplantation is considered to be the optimal treatment for end stage kidney disease in biomedical models (Cameron et al. 2000; McDonald & Russ 2002), Indigenous Australians with end stage kidney disease are allocated kidney transplants at inequitable rates in comparison to non-Indigenous patients (Khanal et al. 2018). Dialysis treatment is the most common form of treatment for end stage kidney disease and involves the mechanical filtering of blood by a dialysis machine to remove waste from the body (Australia and New Zealand Dialysis and Transplant Registry 2018; Stumpers & Thomson 2013). Haemodialysis, the most common form of dialysis performed in the Northern Territory, is typically performed for four to six hours, three times a week (Australia and New Zealand Dialysis and Transplant Registry 2018; Gorham 2001).

Northern Territory dialysis services operate through a 'hub and spoke' service delivery model (Figure 2). The urban centres of Darwin and Alice Springs function as 'service hubs' that comprise hospital-based dialysis wards, maintenance dialysis services at urban treatment centres known as satellite units and other specialist services (Northern Territory Government 2017b). Service hubs oversee the governance of dialysis throughout the Northern Territory. All patients with new diagnoses of end stage kidney disease commence treatment at hospital renal wards, and are subsequently referred to maintenance dialysis treatment, usually at a satellite unit (Northern Territory Government 2017b). Most dialysis services in the Northern Territory are provided by the Northern Territory Department of Health (Australia and New Zealand Dialysis and Transplant Registry 2018).

Figure 2 Northern Territory dialysis services



Credit: Produced by Stefanie Puszka using Northern Territory Department of Health (2019b) data

Access to dialysis in remote areas of the Northern Territory remains poor. Approximately 85% of all Northern Territory dialysis patients relocate from remote communities to Darwin and Alice Springs in order to access treatment (Gorham et al. 2019). Self care dialysis programs enable patients and their carers to receive training to perform their own treatment, including in unstaffed facilities in remote areas. However, few patients in the Northern Territory perform self care dialysis and many self care dialysis facilities in remote communities remain unused or under-used (Gorham et al. 2018; Figure 2), as will be explored in Chapter Four. Mobile dialysis trucks were pioneered by Northern Territory renal services to enable patients receiving treatment in urban centres to make return visits to their communities. However, the small number of vehicles have also been under-utilised due to a lack of funding dedicated to staffing them, with one truck in Central Australia sitting dormant in a car park for six years before being donated to an Aboriginal Community Controlled Health Organisation (Paech 2019). The relatively small number of nurse-assisted dialysis services that exist in remote Indigenous communities and regional centres are often insufficient to provide treatment to all patients from a particular community or town and its surrounding area.

The funding and governance of Northern Territory renal services

The lack of renal services in remote areas of the Northern Territory can be attributed to a complex mix of logistical, medical, financial and political factors. Dialysis is a highly technical form of treatment and dialysis services in remote areas are complicated by factors such as insecure power supply, variable water quality and supply, climatic extremes and human resource challenges (Gorham et al. 2005; Hoy 1998; Thomas, M 2004; Villarba & Warr 2004). Dialysis is a costly form of treatment and direct treatment costs of urban satellite nurse-assisted dialysis in the Northern Territory were estimated to be around $86, 000 per patient per year on average in 2017, with equivalent costs of nurse-assisted services in remote areas estimated to be $120, 000 - $125, 000 per patient per year (Gorham et al. 2019). As I will discuss in Chapter Seven, medical protocols prevent patients defined as unwell from receiving treatment in remote areas.

Long-running jurisdictional disputes between the Commonwealth and Northern Territory Governments about responsibilities for renal services in remote areas have historically resulted in an absence of government funding sources for remote nurse-assisted dialysis services. Nurse-assisted dialysis services in remote communities have generally been funded in unconventional and, at times, questionable ways. In 1998, Jawoyn traditional owners entered into an arrangement with the Northern Territory Government to relinquish a land rights claim in exchange for a dialysis unit and an alcohol rehabilitation centre in Katherine[1] (Loff & Cordner 1998). In 2000, Aṉangu from remote Central Australia raised over $1 million through an auction of their own art and other works to establish Purple House[2], an Aboriginal Community Controlled Health Organisation that continues to provide dialysis services in remote Central Australia (Rivalland 2006). In 2009 the mining company Xstrata (now known as Glencore) agreed to fund a dialysis unit in Borroloola as part of their agreement with Yanyuwa traditional owners to operate the Macarthur River mine (Kearney 2017: 78). The Commonwealth Government agreed to support a nurse-assisted dialysis facility at Yirrkala in 2012 following considerable advocacy mounted by the late Dr M Yunupiŋu, a Yolŋu renal patient, the lead singer of the internationally acclaimed band *Yothu Yindi*, and a former Australian of the Year, and by his allies (Brooks 2015; see Chapter Eight). The Tiwi Dialysis Centre has meanwhile remained the only nurse-assisted dialysis facility funded and operated by the Northern Territory Government in a remote Indigenous community over the past two decades (Gorham 2000).

[1] Katherine is a regional town in which Indigenous people comprise approximately 25% of the population (Australian Bureau of Statistics 2016b). Katherine's hinterland also includes several remote Indigenous communities.

[2] Named after the colour scheme of the organisation's head office in Alice Springs.

Gill Gorham and her collaborators have comprehensively documented the history of Northern Territory renal services, characterising services in urban areas as largely crisis-driven, severely under-resourced and incapable of responding to rapidly increasing numbers of patients (Gorham et al. 2018; Gorham et al. 2005). Despite the low survival rate of renal patients, demand for treatment increased 150% between 2000 and 2014 and at one point, the renal units in Darwin and Alice Springs were the largest in Australia (Gorham et al. 2018). During my fieldwork, dialysis chairs at Royal Darwin Hospital and Nightcliff Renal Unit continued to spill out into former office space and meeting rooms. Renal services in Darwin and Alice Springs continue to operate beyond capacity, relying on patient non-attendance and a policy of deferred treatment, in which insufficient capacity to provide dialysis to all presenting patients on a particular day is addressed by deferring the treatment of healthy patients to the following day (Gorham et al. 2018; Gorham et al. 2005). Renal health professionals I interviewed reported that the treatment of patients was deferred on a daily basis and described this practice as representing 'sub-standard care'.

In 2018 the Commonwealth Government announced a new Medicare item for remote dialysis services, bringing to a conclusion several decades of disputed jurisdiction over dialysis performed in remote areas (Australian Government Department of Health 2019). Aboriginal Community Controlled Health Organisations providing dialysis in remote areas can now claim reimbursement for some of the costs of employing renal nurses and renal-trained Aboriginal Health Practitioners. Although the policy change does not cover all of the costs associated with providing renal services in remote areas, the number of dialysis services in remote areas of the Northern Territory is likely to expand over the coming years. Concerns about the medical risks to vulnerable patients of receiving treatment in remote areas continue to prevent some patients from returning to their communities, however, as Chapter Seven will explore. The problem of end stage kidney disease amongst Indigenous people in the Northern Territory and poor access to treatment is a problem of care that emerges from the ways in which healthcare systems and governments construct their responsibilities to patients.

A problem in and of Northern Territory political economy

The problem of care for Northern Territorians with end stage kidney disease is a problem in and of Northern Territory political economy, intertwined with predicaments of Australian federalism and reliance on global capital and global markets. The Northern Territory is a vast, sparsely populated jurisdiction, encompassing a tropical north and arid south. The Australian Bureau of Statistics classifies all of the Northern Territory as 'remote' or 'very remote', except for the capital of Darwin, which is

classified as 'outer regional' (Australian Bureau of Statistics 2006). Of the total population of approximately 230, 000, Indigenous people comprise approximately 30%, a substantially higher proportion than any other Australian jurisdiction, and large socio-economic and health inequalities exist between Indigenous and non-Indigenous Territorians (Australian Bureau of Statistics 2016a). The formal economy of the Northern Territory is characterised by the predominance of export-oriented mining and pastoral industries, major construction projects (particularly associated with mining), a relatively large public sector; to a lesser extent, tourism; and a lack of industrial activity (Northern Territory Government 2019). Rolf Gerritsen (2010) describes the Northern Territory formal economy and its reliance on natural resources as exhibiting 'growth without development'. The fiscal weakness of the Northern Territory Government, and thus its ability to provide renal services, is linked to a small tax base[3], high levels of disadvantage amongst Indigenous Territorians and poor economies of scale (Gerritsen 2010). In 2017-18, 47% of Northern Territory Government revenue flowed from Commonwealth Government grants (Northern Territory Government 2017a).

Renal services are embedded in interdependencies between Indigenous Territorians, governments and natural resource-based industries that are intrinsic to the political economy of the Northern Territory. The dependency of Indigenous people on governments, through social security and government services, has often been problematized. In conservative and neoliberal discourses, dependency has tended to figure as a personal or cultural trait that is argued to impede autonomy, market or government efficiency and development (Hughes, H 2007; Sutton 2009). Through the neo-Marxist frame of welfare colonialism, meanwhile, economic dependency is held to limit the political self-determination of Indigenous collectivities (Beckett 1987; Raynes 2000). Dependencies between Indigenous Territorians and governments, however, are not unidirectional (Lea 2006). The funding formula administered by the Commonwealth Grants Commission enables the Northern Territory Government to receive a substantially larger sum of Commonwealth grants relative to its population, in comparison to other States and Territories, largely due to weightings given to Indigenous and rural and remote populations (Productivity Commission 2017). Mining, pastoral and tourism industries, including ventures on land on which Indigenous ownership is recognised in Australian law, connect both government development agendas and Indigenous royalty incomes to global capital and markets.

Yet such interdependencies have often been characterised by conflict, and in the last 15 years, contestation over the extent of governments' responsibilities of care for Indigenous people living in remote areas has intensified. The Northern Territory Government, while sustaining a small tax base,

[3] The Northern Territory Government receives little direct revenue from mining and pastoral industries (Lea 2006; Northern Territory Government 2017a).

also spends a lower proportion of its budget on health services than other States and Territories despite higher levels of need (Commonwealth Grants Commission 2016). Moral rhetoric has been mobilised through discourses in policy frameworks and within the mainstream media urging greater centralisation of Indigenous Australians into larger remote communities and regional towns in order to facilitate participation in employment in the formal economy and efficiency in government service delivery (Altman 2018b; Markham & Doran 2015). Small communities known as homelands or outstations, usually comprising a single extended family group of fewer than 100 residents and usually situated in very remote areas on land on which Indigenous ownership is recognised, have been key sites of disputed government responsibility (Myers & Peterson 2016). Renal services for patients from remote areas of the Northern Territory are subject to this politics of care.

Yolŋu and their relation to the Australian state: interdependency and contested sovereignty

Yolŋu are an Australian Indigenous society and an aggregation of patrilineal, exogamous clans. Yolŋu country comprises the north east region of Arnhem Land, in the north east corner of the Northern Territory. While archaeologists date the commencement of human occupation of Arnhem Land to at least 65, 000 years ago (Clarkson et al. 2017), Yolŋu articulate unbroken genealogical connections to the landscapes and waterways of their homelands since creation (Morphy, H 1991; Thomson 1949). Yolŋu who continue to reside in north east Arnhem Land live in the larger remote communities[4] of Milingimbi, Ramingining, Galiwin'ku, Gapuwiyak and Yirrkala which were initially established as Christian missions; and in surrounding homelands. A small number reside in the mining town and service centre of Nhulunbuy. Yolŋu rights and interests in land are recognised across much of north east Arnhem Land by the Australian state through land rights and native title determinations; and despite the establishment of missions and the bauxite mine at Nhulunbuy, Yolŋu have not generally been alienated from their land (Morphy, H & Morphy 2006).

For Yolŋu, questions about the extent of government obligations of care to renal patients are inextricably linked to the nature of their relationship to the Australian state. While aspects of Yolŋu social organisation are described throughout this thesis where relevant, in this section I contextualise Yolŋu experiences and responses to the problem of care for renal patients in the uneven and

[4] The term 'remote Indigenous community' is used in this thesis to refer to geographic locations denoted by this term in policy frameworks and by Yolŋu interlocutors, while acknowledging that residents in these places may not consider themselves to be cohesive social or political bodies (Christie et al. 2015).

variegated processes of colonisation through which Yolŋu came to be Australian citizens, and continue to advance claims for the sovereignty of Yolŋu clan-nations within the Australian state. The relatively short process through which Yolŋu came to be recognised as Australian citizens has been characterised by the shifting and contested political status of Yolŋu in relation to the state; and economic and strategic interdependency between Yolŋu and state interests.

Yolŋu were not immune to the frontier conflict that took place across Australia during early contact between Indigenous people and European settlers. From the turn of the 20th Century until the 1930s, incursions into Yolŋu country and the rape of Yolŋu women perpetrated by European and Japanese pearling crews and police officers provoked retaliatory responses, bringing to a head questions about the jurisdiction of Australian law in north east Arnhem Land in 1933 (Dewar 1992; Egan 1996). While a punitive response was discussed within the media and the ranks of the Commonwealth Government, missionaries lured Yolŋu men accused of murder to Darwin, ostensibly for reconciliation talks, implicitly granting clans the status of autonomous political entities engaged in diplomatic relations with the Australian state (Thomson 1983). On arrival in Darwin, however, the men were betrayed and arrested. While one of the men, Takiara, was convicted of murder, his conviction was later overturned by the High Court, but Takiara disappeared following release from jail and is thought to have been the victim of an extrajudicial killing (Dewar 1992). As a punitive raid continued to be discussed, the anthropologist Donald Thomson convinced the Commonwealth Government to allow him to conduct fieldwork in north east Arnhem Land in order to broker peace, again deploying a diplomatic response (Thomson 1983).

Despite early gestures of diplomacy amidst colonial violence, the conflict between Yolŋu and the Australian state subsequently gave way to a relation of paternalism, in which the state attempted to protect Yolŋu from the violence of settlers and to assimilate them into Western economies and lifeworlds. Although state paternalism did not afford Yolŋu the status of Australian citizens, a degree of mutual recognition between Yolŋu and the state emerged in this period. Christian missions in Methodist and Anglican denominations were established in north east Arnhem Land from 1923, and in 1931 the Arnhem Land Reserve was declared, restricting most of the region for use by Yolŋu and other Indigenous people whose country lay within its boundaries; and missionaries (Altman 1987; Keen 2004). Missionaries encouraged Yolŋu to take up Christianity, sedentary life and Western foods; and trained them in manual labour and domestic work (Dewar 1992; Magowan 2001a). While some Yolŋu were drawn into the missions, others never left their homelands (Morphy, F 2010). The embracing amongst Yolŋu of syncretic beliefs through which a Christian God, Jesus and prophets became

recognised as ancestors and incorporated into ancestral myths was encouraged by some, but not all missionaries (Berndt 1962; Morphy, H 2005; Wells, E 1982).

Questions of overlapping territorial claims and interdependency emerged from the shifting alliances precipitated by World War II. While Yolŋu had been arrested for attacking Japanese pearling crews a decade prior, they were enlisted to defend Australia's northern coastline from Japanese attacks during the early years of the war. Donald Thomson was tasked with training and leading a scouting and reconnaissance force of Yolŋu guerrilla fighters (Dewar 1992; Thomson 1983).

Mid-century mineral exploration in north east Arnhem Land brought forth territorial contention between Yolŋu, missionaries, mining companies and the Australian Government. Yolŋu opposed the bauxite mine planned on the Gove Peninsula, expressing their claims of sovereignty within the state through the painting of the motifs of clans from the local area on panels installed at the Yirrkala church and on a bark petition expressing land rights and political autonomy that was presented to the Commonwealth Parliament (Morphy, H 2009; Wells, E 1982). The subsequent *Milirrpum v Nabalco Pty Ltd* case of 1971 was the first time that native title was litigated in Australia. Although the Yolŋu complainants were not successful, and the mine continues to operate, the case paved the way for Indigenous land rights to be recognised through Commonwealth legislation in 1976 (Williams, N 1986). In the 1980s and 1990s Yolŋu were among the instigators of the Barunga Statement and a national campaign for a treaty between Indigenous Australians and the Australian Government which would recognise Indigenous sovereignty within the Australian state (Corn 2009).

The extension of citizenship rights to Yolŋu was accompanied by a degree of recognition by the state of Yolŋu autonomy and cultural alterity. In the 1960s, many citizenship rights were extended to Indigenous people in the Northern Territory including the right to vote, rights to award wages in the pastoral industry and entitlements to some social security payments (Broome 2001). Support for Indigenous self-determination at a national level from the 1970s to 1990s saw the transformation of missions to small towns, and was paralleled by the return of some Yolŋu to their homelands (Peterson & Myers 2016). By the 1980s, all social security entitlements had been extended to Indigenous Australians in remote areas as cash payments, underwriting the homelands movement (Altman & Sanders 1995; Trudgen 2000). From the 1970s, publicly-funded Indigenous organisations delivering health and community services emerged (Bartlett & Boffa 2005) and bilingual education programs were pioneered in north east Arnhem Land schools and elsewhere in the Northern Territory (Devlin et al. 2017). Despite these developments, some Yolŋu leaders expressed frustration at what they described as a shallow form of self-determination that failed to recognise clan sovereignty and accord

clans the status of nations existing within the Australian state through political autonomy (Christie & Greatorex 2004; Yunupingu 2009).

However, Yolŋu leaders have generally opposed the subsequent dismantling of these nascent self-determination structures. In 2004 the Commonwealth disbanded the Aboriginal and Torres Strait Islander Commission which had overseen many publicly funded Indigenous programs and organisations (Watson 2004). In 2007 the Commonwealth enacted the Northern Territory Emergency Response following claims of child sexual abuse and social dysfunction in remote Northern Territory communities (Altman & Hinkson 2007). Through a new paternalism, emergency measures included greater conditionality placed on social security, bans on alcohol and pornography, compulsory leases of Indigenous land by government agencies, the abolition of customary law provisions from sentencing and the transfer of some social services back to the government. Emergency measures were applied to people living on land over which Indigenous ownership was recognised in Australian law, and required the suspension of the Racial Discrimination Act (Altman & Hinkson 2007). While proponents argued that Indigenous autonomy and a preoccupation with political rights had resulted in the neglect of responsibilities of care, many Yolŋu expressed outrage at the erosion of their autonomy (Puszka 2009). The parallel withdrawal of financial support and government services from homelands and the merger of local community councils into regional shires that resulted in many jobs formerly occupied by Yolŋu being filled by non-Indigenous people reinforced these views (Altman 2018b; Puszka et al. 2013). While Yolŋu citizenship of the Australian state is now well established, Yolŋu sovereignty within the state and the nature and extent of government obligations of care to Yolŋu remain highly contested.

Conceptualising care through care scholarship

In the preceding sections I have considered end stage kidney disease amongst Yolŋu as a problem of care associated with poor access to dialysis treatment and displacement from kin and country and intertwined with colonisation and Northern Territory political economy. I have contextualised the problem of care in the interdependent relations between Yolŋu and the state. In the following I describe three major approaches to care scholarship within the social sciences, drawing from the anthropology of care and related sub-disciplines such as medical anthropology and moral anthropology, as well as other social sciences. I review approaches to care scholarship that I describe as attending to the moral value of care, the governmentality of care, and alternative approaches, before situating my own work within care scholarship. While the approaches I outline are broadly

defined, and may contain some overlapping perspectives, they each contribute a different perspective to the recurring tension within care relations between structure and agency.

Care and agency: the moral value of care

One avenue of care scholarship has considered care as a moral commitment central to the human condition. Scholars whose work I loosely describe as invested in the moral value of care have explored how care is valued and gendered. These scholars have tended to emphasise the sensory, affective, embodied forms of labour and knowledge essential to care-giving but often marginalised through non-remuneration of domestic care and in biomedical regimes of value characterised by expert scientific knowledge.

Scholars of the moral value of care have described how practices of care are intertwined with the ways we are constituted as physical and social beings. Through care, we may come to understand our own corporeality (Taee 2017). As a relational practice, care is implicated in processes of personhood and intersubjectivity (Aulino 2012; Buch 2015; Chattoo & Ahmad 2008; Kaufman 2003; Kaufman & Morgan 2005; Thelen 2015), and may conflict with values of autonomy (Da Roit & De Klerk 2014; Dawson & Goodwin-Hawkins 2018; Rapport 2018; Varul 2010). Illness and changing needs for care may transform our identities, subjectivities and social relations (Das 2015; Garcia 2010; Taee 2017). Scholars of this approach have illustrated how biomedicine adopts a liberal construct of personhood, as a status embodied by rational individuals, and attributes people with cognitive deficiencies a social death or little social worth (Chattoo & Ahmad 2008; Kaufman 2003; Taylor 2008). They have described how relational forms of personhood emerge from care-giving practices, in which the person one is and one's place in the world is defined through relations to others. The agency and relational personhood of people who are critically ill or have impaired cognitive function may be sustained through practices of care which constitute or maintain relationships (Chattoo & Ahmad 2008; Hoppe 2020; Kaufman & Morgan 2005).

The production and reproduction of social relations through care has been a central concern of anthropologists of care. The giving and receiving of care may be enacted through relations of gender, interdependency and intergenerational obligation (Alber & Drotbohm 2015; Barnes et al. 2015; Jolliffe & Worland 2018; Kleinman 2013; Smith-Morris 2018). Scholars of contemporary forms of kinship illustrate how kinship may be made through relations of care (Borneman 1997; Franklin & McKinnon 2001). Care has often been described as a gift or a relation of reciprocity (Kleinman 2012, 2013). Relations of care may at once work to sustain social ties and social inequalities, both among kin

(Heinemann 2015; Thelen 2015) and within healthcare systems (Andaya 2009; Kyeong Seo 2016). Expectations and obligations of care may be transformed by the growing magnitude of chronic disease and biotechnologies that prolong life (Da Roit & De Klerk 2014; Das 2015; Manderson & Smith-Morris 2010; Rose 2007; Varul 2010). New technologies of care may redistribute caring responsibilities and reconfigure the ethics of care (Das 2015; Kaufman & Morgan 2005; Willems 2010). As scholars of science and technology studies argue, emerging biotechnologies constitute interdependencies between human and non-human actors in new ways (Dunholt & Langstrup 2012; Puig de la Bellacasa 2017; Willems 2010).

Anthropologists of care and health geographers have described a dialectical relation between the ways in which relations of care are constituted, and the ways that care is spatially inscribed. 'Landscapes of care' or 'therapeutic landscapes' are social, organisational or geographic spaces that emerge through care work (Gesler 1992, 2005; Milligan, C & Wiles 2010; Williams, A 2002). Illness may be intertwined with broader processes of marginalisation and dispossession within social and physical landscapes (Garcia 2010). Healthcare may be enacted differently in hospitals and in homes (Heinemann 2015); intimate care accommodated in homes is likely to differ from the intimate care of nursing homes (Buch 2013; Milligan, C 2003). 'Infrastructures of care' such as houses and medications may work to pattern care practices (Dunholt & Langstrup 2012; Power & Mee 2019).

Feminist scholars of the moral value of care have engaged in normative projects to reclaim the value of care and the productive value of care-givers. Carol Gilligan (1982) contrasted a feminine ethics of care, premised on compassion, negotiation and responsibility with a masculine ethics of justice, characterised by rights, rules and fairness, claiming the legitimacy of women's morality. Joan Tronto (1993) described four categories of care that are differently gendered: caring about, taking care of, care-giving and care-receiving. Tronto argued that the relative value assigned to each form of care serves to reproduce patterns of women's insubordination. Feminist scholars of care have argued that society accrues a social debt to care-givers (Fineman 2004; McCluskey 2002). Some have sought to recast care as 'work', situating care within realms of production and the formal economy (McDowell et al. 2005); and within domains of politics and citizenship (Sevenhuijsen 1998; Thelen 2015; Tronto 1993).

Feminist conceptualisations of care as work that produces social debt have, however, been challenged by scholars of disability and social gerontology. These scholars argue that such framings objectify care-receivers as passive and burdensome (Fine, M & Glendinning 2005; Weicht 2011). Along with some other feminist scholars, they have contested the problematisation of physical, social and economic

dependency, arguing that liberal ideals of autonomy and self sufficiency are modelled on the lives of white, middle class, middle aged, able-bodied men (Barnes et al. 2015; Feder Kittay & Feder 2002; Weicht 2011). Some suggest that analytical attention should be brought to bear on autonomy, agency and interdependency within relations of care; and care should be repositioned as a social responsibility (Fine, M & Glendinning 2005; Rapport 2018; Rummery & Fine 2012; Weicht 2011).

The commodification of care presents a further vexed topic for scholars of the moral value of care. Some have responded to feminist attempts to recast care as 'work' by arguing that market values of autonomy, individual self interest and monetary valuation are antithetical to an ethics of care (Hopper 2001; Kleinman 2013; Rummery & Fine 2012); and that commodification exploits and devalues both care-givers and care-receivers (Buch 2013; Fine, MD 2007b). Baldock (1997) argues that care practices are not amenable to quantification as feelings, values and social relations are fundamental to its effectiveness. Hochschild (1983) describes requirements for 'emotional labour' in feminised service industries as leading to new forms of exploitation. Others meanwhile argue that tropes of the corruption of intimate relations of care by economic considerations are belied by social and economic relations that have long been intertwined through care (Cubellis 2020; Zelizer, V A 2009; Zelizer, V A 2011).

Scholars of the moral value of care have undertaken path-breaking work, opening up new fields of enquiry in the valuing of care and of the forms of relationality and embodied knowledge involved in giving and receiving care. Some accounts, however, tend towards sentimentality and romanticism and engage in gendered and racialised essentialism, neglecting relations of care that may be exploitative, paternalist or coercive. Andrew Dawson and Bryonny Goodwin-Hawkins (2018: 142), for instance, suggest that 'healthcare may not necessarily be caring': here, poor care is excluded from the authors' definition of care. Vincent Duclos and Tomas Sanchez Criado (2019), in their indigenous critique of the anthropology of care, call attention to a tendency towards conservatism and protection in care scholarship that works to support the preservation of existing social orders and attempts to dominate people and nature. Duclos and Criado accuse some care scholars of failing to analyse the entanglement of care with colonialism and inequality. In the following section I consider approaches to care in which structural inequalities and political economies comprise a key analytic.

Structures and governmentality of care

A second approach to care scholarship, which I designate the governmentality of care, has investigated how care is governed and the structural conditions in which care is enacted. Scholars of

this approach have explored the ways in which human life acquires value through care. They have investigated how care participates in global movements of people and capital through global chains of caring labour, medical migration and the global dissemination of biotechnology (Amrith 2017; Baer et al. 2013). Although healthcare has been the predominant object of enquiry for governmentality of care scholars, they have also enquired into the impact of structural forces on domestic care. They have been attuned to the redistribution of caring responsibilities among states, citizens and NGOs through biotechnological innovation and neoliberal health and social policy (Biehl 2007, 2013; Muehlebach 2007, 2012). They have explored how care has been framed as a right and responsibility of citizenship (Chudakova 2017; Prince 2012). Neoliberal states have been described as undermining relations of care in families and abandoning those in need of care (Biehl 2007, 2013; Povinelli 2011).

Medical anthropologists influenced by Foucauldian theory have described how hegemonies of power and knowledge work to govern care. The commodification of bodies and bodily material through biomedicine and global capitalism, including through the gifting and sale of kidneys for transplantation, may inaugurate new forms of exploitation and sacrifice that are disguised in a rhetoric of care and altruism (Scheper-Hughes 2002, 2007). Biotechnological innovation may make possible new ways of governing human conduct (Rose 2007). Some have deployed the Foucauldian concept of biopower, in which the health of populations becomes visible as an object of governance through technologies such as statistics and scientific knowledge (Biehl 2007, 2013; Fassin 2009; Reubi 2018). Biopolitical imperatives may amount to a denial of care, for example, by triaging treatment to patients deemed likely to survive or to maintain productive capacity; by abandoning patients deemed unproductive to oppressive institutions; and by justifying racial apartheid (Biehl 2007, 2013; Fassin 2009). State power may be enacted in the service of managing populations to cultivate medical subjectivities and to mould conduct in ways that deny the social relations in which patients are embedded, for example, by espousing self care regimes that require patients to prioritise their own nutritional needs over their families' (Biehl 2007; Brotherton 2012; Prince 2012). Citizens may enact forms of biocitizenship, in which claims for healthcare are made on the basis of biological status, not rights; and through which value inheres in pain and illness (Fassin 2009; Petryna 2002, 2012; Prince 2012; Rose 2007).

The sub-discipline of moral anthropology has emerged from Foucauldian roots, enquiring into how care for the sick and suffering is legitimated through our moral commitments (Fassin 2012). Scholars of moral anthropology have argued that the universalism of the welfare state has been superseded by a selective moralism in which needs for care become legible through biological and affective registers (Feldman & Ticktin 2010; Ticktin 2011). Humanitarian interventions are accused by scholars of moral

anthropology of mobilising care and compassion through an 'anti-politics' mentality, in which remedial treatment displaces possibilities of addressing structural factors that produce illness and suffering (Ticktin 2011).

Another strand of governmentality of care scholarship grounded in critical medical anthropology, with a genesis in neo-Marxist theory, has engaged in materialist analysis of illness and care. Scholars of this approach have investigated how political and economic forces shape the distribution of illness and care (Castro & Singer 2004; Farmer 2003; Schrecker 2014; Singer & Baer 1995; Whiteford & Tobin 2004). Illness may be understood through this approach as an embodiment of oppression, inequality and alienation (Singer & Baer 1995; Taussig 1980). Scholars influenced by this approach to care have engaged in critiques of biomedicine, arguing that it works to reproduce oppressive and colonial structures (Arnold, D 1993; Baer et al. 2013; Singer & Baer 1995); and that unequal social relations are reproduced in therapeutic relations that disempower patients (Singer & Baer 1995).

Governmentality of care approaches to care scholarship thoroughly attend to the political economies and structures of power in which relations of care are situated. They contribute a critical approach to the reproduction of gendered, racialised and class-based inequalities through caring relations. Such approaches may, however, insufficiently attend to the ways in which power and structural inequalities manifest through the local specificity of relations of care. Subjective experiences and local representations of illness and care relations have not generally been a primary objective of enquiry amongst many of these scholars (although Farmer 2003; Taussig 1980 are exceptions). Governmentality scholars' accounts of illness and care tend to carry the shadow of monolithic states, neglecting how health policy and healthcare may be enacted, subverted, resisted or co-opted through relations between actors in healthcare systems.

Other approaches to the scholarship of care

More nuanced approaches to care scholarship have emerged in several recent ethnographies. Recent works have considered how structural forces are realised in the lives of care-givers and care-receivers and how care may be negotiated, imposed, claimed or contested (eg: Chudakova 2017; Dussart 2010; Garcia 2010; Han 2012; Heinemann 2015; Huang 2015; Kyeong Seo 2016; Macdonald & Mears 2019; Mol 2008; Stevenson 2014; Street 2014). These works consider care as a social and economic relation within families, between health professionals and patients and between citizens and states. While many of these ethnographies of care draw on various approaches and traditions of care scholarship described above, they contribute more ambivalent conceptualisations of care, describing care as an

ongoing process (Mol 2008) or an unstable relation (Han 2012; Street 2014). They attend to tensions in conceptualisations of care as obligation and affective labour, entitlement and gift. Often influenced by the narrative turn in ethnographic writing, these works have tended to privilege accounts of care of marginalised people and communities over contributions to grand theory.

It is alongside these more nuanced approaches to care that I seek to place my own. I draw in particular from disability studies and social gerontology scholars who have inquired into the problematisation of bodily, social and economic dependency through care (eg: Baldock 1997; Fine, M & Glendinning 2005), and from critical approaches that situate relations of care in broader social, economic and political inequalities, while paying attention to their local specificity (eg: Han 2012; Stevenson 2014; Street 2014). In this thesis I explore tensions in the values, relations and expectations of care expressed by Yolŋu, health professionals and policymakers, housing officials, and in policy frameworks. I deploy classic gift theory to consider the divergent expectations of reciprocity invoked by relation of care in families and in neoliberal health and social policy. I investigate how Yolŋu social structures and historic and contemporary marginalisation within the Australian state shape the meanings, expectations and practices of care for Yolŋu with end stage kidney disease.

Care and social value in Australian Indigenous societies

In this section I review how kinship and care have been conceived of as social and economic relations in the anthropology of Australian Indigenous economies. Through this body of literature, I explore how values and practices of care may be constituted in Indigenous families. I introduce the concept of social value, which may be understood as conceptualisations of the 'good life', or in economic parlance, the material and non-material things that people seek to maximise (Gregory & Altman 2018). I explore how relations of care are constituted in Indigenous families in the pursuit of social value.

Through the scholarship of Australian Indigenous economies, I consider how care may be enacted within Indigenous societies through practices of generalised reciprocity, understood as a broad category of material and non-material practices of gifting, sharing and contribution. As conceptualised by Marshal Sahlins, generalised reciprocity is a weak form of reciprocity in which obligations to repay a gift are not well defined in terms of the timeframes, quantity or quality of the return (Sahlins 1974: 193-194). Generalised reciprocity represents a form of long-term social exchange or balance in Indigenous societies in which all members are encompassed in a network of obligations, and through

which temporary social asymmetries or debts have the potential to emerge. Sahlins argued that inequalities of social status, particularly between elders and juniors, may be constituted through practices of generalised reciprocity that promote material equality in such societies.

In this section and throughout this thesis, I deploy the concept of moral economy to explore the values and practices that constitute relations of care in Indigenous families, including values and practices of generalised reciprocity. Moral economy may be understood as the culturally and socially produced expectations about entitlements and obligations associated with the basic needs of life (Scott 1976; Thompson 1991). Moral economies are not necessarily divorced from market economies, but are constituted through social relations and non-capitalist values (Arnold, P 2001; Owen 2009; Palomera & Vetta 2016). Moral economy becomes a particularly salient concept at times of change or crisis, including in indigenous societies' encounters with states and market capitalism, when underlying values and expectations may be thrown into relief (Gregory & Altman 2018; Scott 1976; Thompson 1991)

In this more specific review, I discuss in some depth the work of scholars who have considered care and social value in Indigenous domestic moral economies, and implications for Indigenous peoples' relationship to the Australian state. I discuss the work of five key scholars who have made substantial contributions to understanding Australian Indigenous relations of care, and who have enjoyed broad influence in Australianist anthropology. I then synthesise their conceptualisations of care and discuss the questions about the care for renal patients that they prompt.

Fred Myers (1986), in his influential ethnography of Pintupi society, contributed to Australianist anthropology the notion of nurturance as a representation of hierarchy. Myers described a tension in Pintupi society between values of relatedness, enacted by showing openness to others, and autonomy, through a reluctance to impose authority over others' behaviour or accept constraints on oneself. Myers argued that this tension between autonomy and relatedness is resolved through elders' moral authority, derived from the responsibility they accept to care for the young. Myers described a specific instance of Pintupi relations of care constituted through practices of generalised reciprocity and inequalitites of status. He explored how older men in appropriate categories of relation to boys bear responsibility for nurturing them into men through initiation ceremonies. The transformation of boys into men creates social debts to elders that can never be fully repaid, legitimising elders' authority. However, such social debts are encompassed in broader forms of social exchange over the lifecourse.

Myers' schema of reciprocities of care over the lifecourse also provided a template for conceptualising Pintupi expectations of the state. Myers argued that Pintupi legitimate the authority of the state through expectations that the state will assist them and care for them materially, via client-patron relationships with local 'government bosses'. Pintupi expectations of their relations with state actors, including health professionals, of benefits in exchange for inequalities of power were, however, rarely met. Attempts amongst local non-Indigenous health professionals to foster community control of local healthcare services did not reflect Pintupi expectations of 'government bosses', according to Myers. Young Pintupi women employed as Indigenous Health Workers within local healthcare services faced contending demands on their labour through their professional and social roles.

As in Myers' approach, Basil Sansom explored reciprocity and exchange in Indigenous relations of care. While Myers described intergenerational reciprocities, Sansom considered reciprocities of a more proximate temporality. Sansom, who conducted fieldwork in Darwin town camps that may have included Yolŋu residents[5], described mutual assistance among residents incorporating monetary loans and immaterial help (Sansom 1980, 1982, 1988). He argued that both forms of assistance were represented by residents as the rendering of services to one another. In a 'grammar of service' described by Sansom, 'signal services' that countered spiritual, physical and social threats, such as a loan that enabled a fine to be paid and jail time to be avoided, were highly valued among residents. Residents could earn discounts on financial debts through their performance of 'signal services' to their creditors (Sansom 1988). Sansom described the existential debts that seriously ill people acquired to their carers, who came to own the patient's illness biography, such that only carers could re-tell the 'sick story' (Sansom 1982). Sansom, however, also noted that town camp residents maintained commitments of care to children and incapacitated elderly people beyond exchange relations (Sansom 1988). Sansom foregrounded agentive dimensions of social relations, conceptualising kinship as sets of performative relations that are affirmed and sustained through practices of care (Sansom 1988).

Nicolas Peterson has approached the production of social value in Indigenous societies through practices of generalised reciprocity and processes of personhood, through work with Yolŋu and Warlpiri. Without explicitly addressing practices of care, Peterson describes Indigenous personhood as achieved through relatedness. One's relations to kin define who one is, through universal systems of kin classification in which all social relations can potentially be encompassed, and which give rise to obligations and entitlements in relation to others (Peterson 2013; Peterson & Taylor 2003). Peterson

[5] Yolŋu comprise one of the largest Indigenous collectivities in numerical terms in the Northern Territory and are thought to represent the largest group present in Darwin (Christie & Greatorex 2004).

argues that relational modes of personhood may be realised through practices of generalised reciprocity, including through his own concept of 'demand sharing'. Practices of demand sharing, according to Peterson's formulation, sanction requests made between kin for material objects (Peterson 1993; Peterson & Taylor 2003). As a distributional repertoire, demand sharing requires the bearers of objects to give generously upon request and does not create material debts amongst receivers. While refusing a demand made by a member of one's kin network may lead to an accusation of the denial of the relationship, demand sharing represents a negotiation of social relations as the volume of requests made to any individual is likely to exceed their personal means to respond (although strategies of evasion may be preferable to outright refusal). Peterson characterises Indigenous domestic moral economies as constituted through demand sharing practices and founded on values and principles of generosity, kinship, relational personhood and an indirectness of speech that makes refusal difficult. He suggests that domestic moral economies and demand sharing practices persist due to Indigenous Australians' exclusion from the formal economy and their receipt of state welfare (Peterson 2013; Peterson & Taylor 2003).

Gaynor Macdonald has synthesised the work of Myers, Peterson and Sansom, characterising care as constitutive of personhood, kinship and hierarchies of status in Wiradjuri society. Macdonald argues that Wiradjuri produce social value through practices of 'caring and sharing', including through the demand sharing practices originally described by Peterson (Macdonald 2000, 2018). Drawing on Myers and Sansom, Macdonald describes Wiradjuri expectations of caring and sharing as applying to the sharing of material items as well as gifts of labour. Caring and sharing provides a framework for recognising and responding to the needs of kin without compromising personal autonomy. Wiradjuri acquire authority and social value through 'allocative power', or the capacity to respond to the demands of kin by distributing material and non-material things of value. One's allocative power is not measurable by the financial value of what one gives, and the distribution of items acquired through one's labour, skill or knowledge is particularly valued. Wiradjuri personhood is constituted through caring and sharing practices, through the recognition bestowed by givers on kin and their needs; and in the recognition of recipients of the authority of givers with allocative power.

Macdonald suggests that Wiradjuri relations and practices of care may conflict with the expectations and practices of social policy and healthcare services. She argues that allocative power is compromised by social security which is not acquired through personal effort and which only provides a minimal income (Macdonald 2018). Allocative power is also compromised by state programs administered through Indigenous organisations, such as housing schemes, that distribute resources through bureaucratic rules (Macdonald 2000, 2018). The value placed on personal autonomy by

Wiradjuri and their investment of time in social relations may also trouble their participation in healthcare services that require one to keep appointments and care for oneself in strictly defined ways (Heil & Macdonald 2008).

In a contrasting approach, Jon Altman has considered how social value is produced in Indigenous economies through relations of production. While not specifically addressing relations of care, Altman attends to practices of provisioning amongst Gunwinggu living in Western Arnhem Land homelands, and what we might consider to be material dimensions of nurturance. Altman argues that Gunwinngu living in homelands value subsistence production, food security, living on the land, meaningful labour, egalitarian distribution over accumulation and collective autonomy (Altman 1987, 2018a). These values may be achieved through hybrid economies that integrate market, state and customary economic resources and transactions (Altman 2001, 2007). Social security and commodified resources such as vehicles, guns and certain Western foods have been integral to sustaining hunter-gatherer food production in contemporary times, and have become subject to customary forms of exchange and reciprocity such as demand sharing practices. Material and non-material customary resources have concurrently been deployed in the production of commodified goods such as art; and collective labour and customary knowledge have been mobilised through government schemes such as in Indigenous ranger programs known as 'caring for country' initiatives. Altman further argues that through hybrid economies, Indigenous people living in homelands have made a trade-off, foregoing some citizen entitlements such as better access to healthcare, mainstream education and social housing (Altman 2001, 2007). The social values that Gunwinngu seek to realise by living in homelands are increasingly becoming threatened by the neoliberal state that has attempted to transform homeland residents into participants of formal labour markets and has compromised hybrid economies (Altman 2018a, 2018b).

Myers, Sansom and Macdonald, who all explicitly attend to Indigenous relations of care, suggest that care practices are fundamental to the realisation of social value in Indigenous domestic moral economies. They suggest that Australian Indigenous societies may not make strong distinctions between material and non-material forms of care. We may infer from Altman's work and the other scholars' conceptualisations of care that care is implicated in relations of production as well as distribution and exchange; and that relations between Indigenous people and their country may also be considered to be relations of mutual nurturance. Care is subject to expectations about sharing and generalised forms of reciprocity; and figures strongly in inter-generational relations and in the constitution of social status, hierarchy and authority. These scholars also suggest that care is critical to the realisation of Indigenous personhood, through the performance and recognition of kin

relationships. However, Myers, Sansom, Peterson and Macdonald provide differing accounts of how social debts emerge through relations of care in specific cirscumstances. The work of Myers, Sansom and Macdonald also suggests that care and nurturance may not be exclusively constituted through women's social roles in Australian Indigenous societies.

Most authors cited above suggest that Indigenous relations of care are also implicated in Indigenous peoples' expectations of the state, albeit in different ways. Myers suggests that Pintupi expectations of familial care may also apply to their expectations of street level bureaucrats as agents of the state; and Myers and Macdonald both suggest that street level bureaucrats such as health professionals may be inattentive to the relational dimensions of care that are foregrounded in Indigenous societies. In Altman's integrative model, meanwhile, state resources are critical to maintaining hybrid economies and, we might infer, also integral to maintaining relations of care among kin. It appears likely that the withdrawal of welfare resources will have implications for relations of care within Indigenous families.

Conceptualising the problem of care for Yolŋu renal patients: Research questions and thesis overview

Care scholarship and the scholarship of Australian Indigenous economies prompt a query about how we might then understand relations of care for renal patients, as unwell and often elderly people, in Yolŋu domestic moral economies and as Indigenous citizens of the Australian state. In this thesis I bring together this literature to consider how care is practiced and valued as a relation in the domestic moral economies of Yolŋu families, between health professionals and Yolŋu renal patients and between Yolŋu citizens and the state. As care is conceptualised in this thesis as a relation encompassing both material and non-material dimensions, I explore the care of the state through health and social policy. I take cues from the anthropology of policy and of the state to understand health and social policy as assemblages of organisational forms, practices, protocols, actors and narratives which may be contradictory (Tate 2015; Trouillot 2001).

In investigating values and practices of care in Yolŋu domestic moral economies and in public policy, I consider the social meanings attributed to relations of care, and how they inform the ways that obligations and entitlements of care are constituted. I explore how dependency is legitimated, problematized or obscured in relations of care. I critically analyse what the care for Yolŋu renal

patients by the state can tell us about the way in which Yolŋu citizenship of the Australian state is constituted. In order to do so, I pose the following research questions:

- How is the care for Yolŋu renal patients practiced and valued in Yolŋu domestic moral economies and in health and social policy?

- How do the multiple values and practices of care for Yolŋu renal patients in Yolŋu domestic moral economies and in health and social policy interact?

- What are the implications for relations between Yolŋu and the state?

I argue that giving and receiving care is understood by Yolŋu primarily as a relationship between generations, and may provide a means of exercising power and responsibility within gendered and age-based social roles. Care is enacted through interlocking material and non-material reciprocities in Yolŋu domestic moral economies.

I show that while some of the care needs of renal patients are recognised in health and social policy, the everyday subsistence struggles of their carers and other kin are often neglected in public policy embodying neoliberal values of self care, self sufficiency and responsibilisation. My research reveals how the neoliberal state relies on social relations and care practices in Yolŋu families, constituted through fundamentally different values, to realise health and social policy agendas and to satisfy the basic needs of life of Yolŋu citizens. Yolŋu care practices such as performing domestic labour rather than working in the formal economy, sharing, extending shelter to kin, and hunting and gathering are mobilised yet marginalised by the neoliberal state. Neoliberal values of care are parasitic on social roles within families and in some cases may strain relations among kin, reproducing bodily, social and economic precarity.

I offer an original contribution to scholarship by describing a Yolŋu ethics and practice of care and how it interacts with health and social policy. By considering the intertwining of social and economic, material and non-material dimensions of care, my thesis challenges received ideas about Indigenous dependency on state welfare. I show that an interdependent but unequal relationship exists between Yolŋu families and the state, through health and social policy agendas, in satisfying the basic needs of life of Yolŋu renal patients and their kin. Such interdependencies become particularly salient in times of post-universal, conditional healthcare and welfare. In some circumstances, they also provide a

means by which Yolŋu may exercise political power and compel the state to recognise their care needs.

Chapter One describes my approach to the problem of care for Yolŋu renal patients. I describe my methodological approach of an ethnography of encounter and discuss how I have addressed the limitations and ethical issues that arose in my research. I describe my field site of Darwin, attending to the ways that Darwin may be lived in and experienced by Yolŋu as well as the predominantly non-Indigenous street level bureaucrats and policymakers tasked with providing them with care.

Chapter Two contextualises the care for Yolŋu renal patients in Yolŋu beliefs, values and practices associated with health and in patients' and families' experiences of kidney disease. I draw on the ethnographic record and empirical data to describe Yolŋu beliefs and practices pertinent to kidney disease, showing that Yolŋu connect embodied vitality to social relations and relations between people and country. I analyse Yolŋu experiences of kidney disease as embodied and social forms of suffering. I introduce concepts and framings that will be expanded on in subsequent chapters. I show that for Yolŋu, end stage kidney disease and urban displacement are experienced as problems of physical and social displacement; of sedentarisation; of altered social roles and social status; and of personhood and agency. I argue that for Yolŋu renal patients, dependency on unknown health professionals and foreign dialysis machines are rendered problematic, not as a lack of independence, but through an absence of relationality.

In Chapter Three I consider how the care for Yolŋu renal patients is practiced and valued in Yolŋu domestic moral economies. I describe an ethics of care in Yolŋu families. I show that the care for renal patients invokes gendered and generational relations of respect, interdependency and generalised reciprocity in Yolŋu domestic moral economies. I argue that for Yolŋu, domestic care is integral to the production of social value in people, relationships and family solidarity. The care of renal patients may reinforce expectations and norms associated with specific kin relations, yet relations of care also require considerable agency to maintain. I describe how Yolŋu care practices and relations have adapted in response to urban displacement.

Chapter Four, Five and Six consider how Yolŋu attempt to realise such values and practices of care through health and social policy; and how health and social policy agendas are constituted through other values and practices of care, yet also rely on Yolŋu care practices. Chapter Four considers how Yolŋu renal patients attempt to enact care that expresses respect, attentiveness to individual bodies, generalised reciprocity and interdependency through their relationships with health professionals in

renal wards and units. I also explore how health professionals conceptualise the care they provide to patients as productive of social debt and dependency. I argue that health professionals express desires to restore equality to therapeutic relations and attempt to cultivate patient empowerment, independence and self care. Paradoxically, when health professionals' attempts to enact patient self care are not realised, some health professionals legitimise paternalistic practices of healthcare. I examine self care dialysis regimes and Yolŋu patients' proposal for their younger relatives to be trained to administer dialysis as particular sites through which conflicting values and expectations about the reciprocities of care are brought into relief. I suggest that both self care dialysis and the patients' proposal deploy relations of care constituted through Yolŋu domestic moral economies in the delivery of healthcare.

In Chapter Five I attend to Yolŋu renal patients' practices of providing shelter to visiting and resident kin who provide domestic care to them through practices of generalised reciprocity in Yolŋu domestic moral economies. I consider how the governance of housing in the Northern Territory, embodying particular conceptualisations and values of care, intersects with Yolŋu values and expectations of care. I argue that the Northern Territory Department of Housing, Local Government and Community Development mobilises categories of legitimate and illegitimate housing dependency in the allocation of public housing in Darwin, and casts public housing as a resource for instituting hygiene and sanitation within nuclear families. Renal patients, generally considered to be legitimately dependent in housing policy, are more likely to be allocated public housing than their kin. Yet, through extreme public housing shortages and Yolŋu care practices, Yolŋu renal patients become housing providers to their extended kin networks. Renal patients who provide shelter to visitors without other accommodation prevent them from sleep rough, but inadequate public housing and such practices can lead to crowded dwellings. I argue that despite disparate values of care in housing in Yolŋu domestic moral economies and in Northern Territory housing policy, the state relies on Yolŋu care practices of extending shelter to kin to prevent rough sleeping in Darwin.

Chapter Six explores how social security payments articulate with social roles and practices of generalised reciprocity in Yolŋu domestic moral economies in the presence of end stage kidney disease. I show that similarly to housing policy, values of self sufficiency and categories of legitimate and illegitimate dependency are mobilised in social security policy, through different rates and conditions of payment of the Disability Support Pension, Age Pension, Carer Payment and Newstart Allowance unemployment benefits (now known as the Jobseeker Payment). Categories of legitimate and illegitimate dependency may lead to material inequalities between renal patients, who are often eligible for higher rates of payment such as the Disability Support Pension or Age Pension, and their

kin, who often receive unemployment benefits. Material inequalities among kin and the insufficient subsistence offered by unemployment benefits could reinforce renal patients' obligations to share money and food with their extended families. I argue that social security policy relies on Yolŋu sharing practices, enacted through Yolŋu values of care, to provide Yolŋu receiving unemployment benefits with a basic material subsistence. In Chapter Four, Five and Six I argue that asymmetric interdependencies exist between Yolŋu and the state through health and social policy; and health and social policies that rely on yet marginalise Yolŋu relations of care can strain relations among kin, reinforcing bodily, social and economic precarity.

In Chapter Seven I consider the consequences for Yolŋu and for state policy agendas when healthcare systems fail to realise the value of interdependent relations between Yolŋu and the state in caring for patients. Returning to the topic of health policy, I show that the realisation of social value in Yolŋu domestic moral economies ultimately requires dialysis to be made available on country. I also discuss the evaluations of dialysis services in remote Indigenous communities that show that patients undertaking treatment in their communities have better biomedical health outcomes, better adherence to treatment and lower rates of hospitalisation. Through analysis of patients' and health professionals' experiences of a trial of dialysis at Galiwin'ku, I argue that remote renal services rely on sets of social relations in patients' communities to care for patients and improve their health. Analysing how healthcare systems construct their responsibilities to renal patients through the social constructs of medical risk and professional duty of care, I show that health professionals and policymakers cast remote Indigenous communities as places that present risks to patients' bodies and lives, and cast patients from remote communities as vulnerable dependents, necessitating dialysis treatment provided through urban displacement for many patients. I argue that in Northern Territory renal services, in which patients are cast as dependents, the failure to recognise the potential value of interdependent relations between families and healthcare systems in sustaining patients prevents the realisation of certain health policy agendas and poses existential threats to Yolŋu.

Chapter Eight analyses how Yolŋu make claims for public funding of dialysis services in their communities by mobilising interdependencies of care and concepts of balanced exchange, while acting within prevailing neoliberal conditions of health policy. I explore how Yolŋu funding proposals for dialysis services are intertwined with broader Yolŋu objectives of achieving the recognition of Yolŋu clans as nations within the Australian state. I show that funding proposals draw on the practices of care in Yolŋu domestic moral economies and Yolŋu organisations' willingness to make financial co-contributions in attempts to compel governments to recognise Yolŋu healthcare needs and Yolŋu nationhood. I argue that Indigenous sovereignty within settler states can be understood as a relation

of care, as an understanding between Indigenous nations and the state of their relation and of what they owe one another. The recognition of Indigenous sovereignty requires recognition of the fundamental inderdependency between Indigenous nations and settler states, and requires moving away from discourses of Indigenous dependency.

The Conclusion draws together the major findings to respond to the research questions and considers the implications for how we conceptualise the care of the state and Indigenous citizenship, and how we value people and their care.

Chapter One
Approaching the problem of care for Yolŋu renal patients

In this chapter I describe my approach to the problem of care for Yolŋu renal patients. I discuss my use of the methodology of an ethnography of encounter and my response to the ethical issues that arose in my research. I also describe the research setting of this ethnography, Darwin, the capital of the Northern Territory of Australia. I attend to the different ways the town may have been inhabited by my Yolŋu interlocutors and by the predominantly non-Indigenous policymakers and street level bureaucrats (such as health professionals, community workers and housing department officials) tasked with providing them with care. Finally, I discuss the limitations of my approach.

Methodology

Many dimensions of care escape the verbal, and understanding values and practices of care requires a particular intimacy and immersion. In this thesis I adopt an epistemological stance in which at least some meanings and values of care may be grasped by observing care practices and by listening to interlocutors' care narratives, following Alber and Drotbohm (2015). In exploring the care of Yolŋu with end stage kidney disease, I undertook an ethnography of encounter (Faier & Rofel 2014). Through such a methodology, I approached values and practices of care in encounters: among kin, in therapeutic relationships, at the customer service counters of government agencies. In order to study encounters of care, I sought to understand the multiple perspectives of care-givers and care-receivers. I undertook 16 months of ethnographic fieldwork from September 2017 to February 2019 with multiple cohorts of interlocutors, requiring different methods and positionalities. While my primary interlocutors were Yolŋu renal patients and their families, I also conducted research with agents of state-sponsored care, through interviews with health professionals, health policymakers and housing officials and limited observational research with health professionals. My attempts to consult and conduct research with the staff of the Australian social security agency, Centrelink, were refused. My

research primarily took place in Darwin, the capital of the Northern Territory, where the vast majority of Yolŋu renal patients receive dialysis treatment, in addition to three brief trips to north east Arnhem Land.

As Indigenous researcher Karen Martin Booran Mirraboopa (2003) notes, research is a way of knowing, being and doing in relation to others. While anthropology is inescapably tied to the Western academy and colonial histories, an ethical anthropology requires ethically and politically committed modes of enquiry. Ethical anthropology requires developing representations of interlocutors' social worlds that are tied to interlocutors' own representations, as well as a commitment to ethical research practice that attends to the ways of knowing and being that research methods cultivate (Geertz 1973; Tuhiwai Smith 1999). It necessitates an unashamed constructivism that abandons objective distance in favour of intimacy and purpose (Bornstein 2007; Scheper-Hughes 1995). As a Caucasian researcher, it required me to interrogate my own worldview and some established traditions of anthropology associated with the observation and representation of interlocutors. In an attempt to develop an ethically and politically committed project, I worked collaboratively with two Yolŋu co-researchers who were elders with lived experience of end stage kidney disease. Co-researchers assisted me to develop culturally appropriate study methods and to interpret the data, however the contents of this thesis represent my analysis and I am ultimately responsible for them. Conducting a collaborative ethnography of care also presents several further ethical issues of positionality, power and informed consent, which I address throughout this section.

Consultation and ethical approval

In order to undertake this research project conducted in collaboration with Yolŋu, and situated primarily on Larrakia country, I consulted with 26 individuals and organisations, including Yolŋu elders and leaders; Yolŋu, Larrakia and other Darwin-based Indigenous organisations; and other service providers, government agencies and NGOs. Ethical approval for this project was granted by the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research and its Aboriginal Research Ethics Sub-Committee (17-2921), the Charles Darwin University Human Research Ethics Committee (H17133) and the Australian National University Human Research Ethics Committee (2017-760). This research was also approved by the Northern Territory Top End Health Service, Miwatj Health Aboriginal Corporation, Laynhapuy Homelands Aboriginal Corporation and the Northern Land Council.

Working with Yolŋu co-researchers

Like care, ethnographic research is a relational practice. This thesis owes its existence in its present form to my relationships with two Yolŋu co-researchers who were engaged as advisors, Ms Yinin Dhurrkay and the late Mr Muŋuḻpurr. My previous work with Yolŋu and other Indigenous Australians impressed on me the need for and benefit of engaging co-researchers who can help broker relationships with potential interlocutors; who can advise on the conduct of research according to Indigenous protocols of interpersonal relationships; who can steer an outsider anthropologist around sensitivities and taboos. Co-researchers can act as an intermediary between an outsider researcher and interlocutors. To assist with the process of brokering relationships with potential Yolŋu interlocutors of any gender, I sought to engage a male and a female co-researcher. I was eventually put in contact with Yinin and Mr Muŋuḻpurr through existing relationships with other Yolŋu.

Yinin is a highly skilled interpreter with previous experience working in research. She was caring for her sister who was undertaking dialysis in Darwin during much of my research, and has many other close relatives who have been diagnosed with end stage kidney disease. Mr Muŋuḻpurr had been undertaking dialysis in Darwin for about 14 years when I first met him. He was a clan leader and had previously worked as a police liaison. Along with other patients, he had been campaigning for improved access to nurse-assisted dialysis in north east Arnhem Land. Yinin and Mr Muŋuḻpurr chose to undertake a Certificate II Community Health Research offered by Menzies School of Health Research as part of their work with me. Aspects of fieldwork (eg: seeking informed consent from Yolŋu interlocutors, presenting our research to service providers) were integrated into the assessment criteria of the course. Both graduated in early 2019.

While formally I related to Yinin and Mr Muŋuḻpurr as an employer and trainer, predominantly we related to one another as fictive kin. Not long after we started working together, Mr Muŋuḻpurr decided to adopt me as his *gathu* (daughter), and this meant that I related to Yinin as a *galay* (cousin or sister-in-law). Due to our differences in age, I was positioned as the student of both Yinin and Mr Muŋuḻpurr.

Being positioned in a tutelary relationship with Yinin and Mr Muŋuḻpurr worked to some degree to displace the power relations inherent in employee-employer relationships, and their advice generally guided how fieldwork was conducted. A tutelary 'fictive kin' relationship also granted me considerable access to fieldwork sites in Yolŋu and Balanda worlds. At one point, when negotiating institutional approval to observe a trial of dialysis treatment at Galiwin'ku, Mr Muŋuḻpurr exclaimed, 'I'm your

passport!', making reference to his status as a traditional owner, and indeed he often was, extending to me invitations to visit him while he undertook treatment and to accompany him at patient meetings and during the dialysis trial. Although subsequent relationships with other Yolŋu interlocutors also gave me considerable access to the lived experiences of renal patients, it was my original relationships with Yinin and Mr Muŋul̲purr that made this possible. I felt myself to be more indebted to Yinin and Mr Muŋul̲purr than they were to me.

Although the general topic of my research, care for renal patients, was not determined in collaboration with patients or co-researchers, in early consultations, Yolŋu and their service providers often commented that it was an important topic and worthwhile objective of enquiry. I was open to pursuing different directions within the broad scope of the project, and Yinin and Mr Muŋul̲purr did at times make suggestions of this nature. Some suggestions were taken up, such as conducting fieldwork during the Galiwin'ku dialysis trial and attempting to establish a forum for Yolŋu renal patients in Darwin to teleconference into a Miwatj Board meeting. Other suggestions were not, including investigating Tiwi Islanders' experiences of nurse-assisted dialysis at Wurrumiyanga, conducting fieldwork at the prison and investigating financial support for funerals. The possibilities of a more collaborative approach to research within this project developed over time along with my relationship with co-researchers, and were contingent on it.

It was not my original intention to elicit co-researchers' narratives of end stage kidney disease alongside those of other Yolŋu s. The nature of Yinin and Mr Muŋul̲purr 's experiences, however, meant that their contributions to interviews and interlocutor discussions, and to discussions with me about interpreting the data, were never abstract. Both shared their personal narratives and made it clear that they wanted their narratives to be included in my research. The status of Yinin and Mr Muŋul̲purr as employees meant that I generally had more access to their time than that of other interlocutors, however this was unlikely to have substantially impacted on the content or the power dynamics of discussions as their personal narratives were generally volunteered without prompting from me. Budget constraints also limited the amount of hours that I could employ Yinin and Mr Muŋul̲purr for each week.

Positionality

When working with renal patients, I deliberately positioned myself outside of healthcare systems. Association with healthcare systems may have impacted on my relationships with Yolŋu interlocutors, and may have caused them to suspect covert surveillance. Approaching renal patients while they were

dialysing would have also raised ethical considerations about consent as patients would have been unable to physically move away from me. My introductions to potential Yolŋu interlocutors were always through co-researchers, taking place in mutually agreed locations such as in their homes and at public places such as parks and reserves, and never in locations of healthcare. I only visited Yolŋu interlocutors at renal wards and units when invited to do so. At the time of the commencement of my fieldwork, I was employed at Menzies School of Health Research to work on a study that also involved collecting data from renal patients at renal wards and units and auditing their medical records. I changed the nature of my employment and ceased working on this study before its data collection phase began in order to avoid being associated with healthcare systems by Yolŋu interlocutors and to avoid gaining access to the medical records of patients who may subsequently become my interlocutors. I explained to interlocutors that I was a student of Menzies School of Health Research as well as the Australian National University, and so I may not have been seen as entirely disconnected from healthcare systems. However, I suspect that my willingness to spend large amounts of time with interlocutors, meet them outside of healthcare locations and interact with them in non-directive ways signalled a different kind of positionality to that of a health professional.

When interacting with Yolŋu interlocutors, I mobilised the positionality of 'fictive kin' in which I had been placed. This status did not equate to 'actual kin' and I was still very much placed in the category of Balanda (a non-Indigenous person), but was also placed in a web of obligations and responsibilities that existed beyond my research. Yolŋu interlocutors did often make many material and immaterial requests of me, of money, food, lifts, for assistance with completing paperwork and interacting with social services. Determining when to oblige and when to politely decline was always a contextual undertaking, and included consideration of those who I was seen to be truly obligated to (generally, Mr Muŋul̲purr 's extended family), although I never declined requests for assistance with paperwork and accessing services. My willingness to assist interlocutors was unlikely to provide an inducement to participation in this research, as requests for assistance were generally made of me after I had established an initial familiarity with interlocutors and they had already agreed to participate in my research. At times, it was difficult to disentangle fictive kin status and my research. For example, Mr Muŋul̲purr, tiring of the food served at the renal unit, asked me to bring him breakfast at the commencement of his dialysis treatments. While this required me to set aside certain Western feminist ideals of emancipation from the gendering of care, it also provided an excellent opportunity to regularly spend time at the renal unit without adopting a form of positionality associated with the healthcare system.

I adopted a different positionality when consulting with and interviewing service providers and policymakers. Prior to commencing fieldwork, I had lived in Darwin for nine years and had worked in the Indigenous health sector for eight years, briefly at the Northern Territory Department of Health, and subsequently at Menzies School of Health Research. Among local service providers and policymakers, being connected to Menzies School of Health Research carries a different status to researchers from 'down south', and might be described as being 'one of us' or 'a local', and was at times one that I sought to mobilise, at others one that came into play without any intentionality on my behalf.

Negotiating the field site

The shifting locations of contemporary ethnography require conceiving of the field in non-bounded ways (Marcus 1995; Passaro 1997). Although the local specificity of Darwin was integral to my research, conducting fieldwork in a place I called 'home' necessitated conceiving of the field not as a geographic location, but as a set of practices, interactions and understandings between myself and my interlocutors that were brought into an epistemological framework. While many of the locations of my fieldwork embodied a mundane familiarity to me, including many public spaces and places of healthcare, conducting fieldwork required occupying spaces of Darwin differently and bringing a new lens to places I knew. Conducting fieldwork in Darwin also required me to attend to the different ways in which intercultural places and spaces may have been inhabited and experienced by Yolŋu interlocutors compared to someone who occupied the middle class non-Indigenous positionality that I did (see following section). For example, East Point Reserve represented to me a site of bitterly contested local triathlons in which an unlucky athlete might suffer foot lacerations from running across shell middens; whereas for my Yolŋu interlocutors, it was a place in which people came to escape town life and be reminded of home, often sitting facing east, where yams and shellfish could be collected. While the mangrove-fringed foreshore opposite my apartment complex represented to me a stunning panorama, for some of my interlocutors it was a place in which cooking fires could be lit to roast magpie geese, away from the surveillance of authorities.

Encountering and recruiting interlocutors

Yolŋu co-researchers brokered introductions to other Yolŋu with end stage kidney disease who were receiving treatment in Darwin, assisted me to explain the project and seek informed consent. I did not realize until later in my fieldwork that Yinin and Mr Muŋuḻpurr had adopted a deliberate strategy of

first introducing me to renal patients who had longer experiences of dialysis and who were mostly elders. I understood this strategy to represent an attempt to commence with introductions to patients who were more comfortable with and confident in discussing their experiences with outsiders; and to delay approaching newer and younger patients about involvement in the research until I was better known within Yolŋu networks in Darwin. Relocating to Darwin and commencing dialysis could be a traumatic experience (see Chapter Two) and new patients may have been unwilling to talk to a stranger. This meant that I collected more data from older patients and those with longer illness biographies. However, it may have also enabled the experiences of newer and younger patients to be included, as these patients may have declined involvement in the research had they not first established a relationship with me. Yinin and Mr Muŋul̲purr sometimes invited newer or younger patients to observe my interviews with patients' older relatives, with consent, so that these patients could appreciate what an interview would involve.

Most Yolŋu interlocutors were connected to the communities of Galiwin'ku, Milingimbi and their surrounding homelands (although several also had other connections to other parts of north east Arnhem Land). They represented a variety of clan and family groups. This was likely a product of Yinin and Mr Muŋul̲purr's personal connections, and may have represented an uneven distribution of end stage kidney disease across north east Arnhem Land at the time of my fieldwork. The association of my interlocutors with Galiwin'ku and Milingimbi also likely reflected the presence of nurse-assisted dialysis services at Yirrkala, and hence the presence of fewer patients from the Yirrkala area in Darwin.

I discussed with Yolŋu interlocutors their desires regarding their identification in published material. Generally, Yolŋu interlocutors wanted to be identified and did not want their personal narratives to become disassociated from their personal identities. Yolŋu generally acquire several names throughout their lifetimes, and interlocutors who wished to be identified determined which of their names would be used in the text. However, a small number of Yolŋu interlocutors did not provide permission to be identified in published material due to their untimely deaths before I was able to ask them about the use of their names. In interviews, Yolŋu interlocutors also at times shared narratives involving relatives who were not involved in my research. In these cases, I have referred to Yolŋu in the text through kin terms or skin names where possible, have otherwise assigned them pseudonyms, or have simply referred to them as 'interlocutors', depending on the nature of the material.

I list the Yolŋu interlocutors named in this thesis in Table 1, describing their age categories, as Yolŋu do, with respect for the knowledge and life experience of older people ('old man' and 'old woman' are respectful terms of address used by Yolŋu). All of my Yolŋu interlocutors were related to one another,

often distantly, and in ways too complex to represent on a kinship chart. In Table 1 I note relationships between Yolŋu interlocutors when they were particularly emphasised by interlocutors themselves.

Table 1 Yolŋu interlocutors named in this thesis

Interlocutor	Background
Mr Muŋul̲purr	A co-researcher who worked with me. An older renal patient from Galiwin'ku cared for by his wife while she spent periods of time in Darwin.
Yinin	A co-researcher from Galiwin'ku who worked with me. A Yolŋu language consultant and carer to her sister, a renal patient.
Bul̲anydjan	An older renal patient from Galiwin'ku cared for by several members of her extended family.
Dianne	A middle aged renal patient from Galiwin'ku cared for primarily by her husband and niece.
Waymamba	An older renal patient from Milingimbi cared for by her daughter's daughter.
Wapiriny	An older renal patient from Galiwin'ku cared for by his wife and extended family. A member of Mr Muŋul̲purr's mother's mother's clan.
Annie	A middle aged renal patient from Milingimbi.
Ŋarritj	One of Bul̲anydjan's carers. A sistergirl in his 20s from Galiwin'ku. I refer to Ŋarritj as a man as he adopted different gender identities in different contexts, but referred to himself in male terms in conversations with me.
Helen	An older renal patient from Galiwin'ku cared for primarily by her daughter. Annie's father's sister.
Jeffrey	An older renal patient from Galiwin'ku. Brother to Mr Muŋul̲purr.
Marcia	A renal patient in her 30s from Galiwin'ku.
Gutjan	A middle aged renal patient from Galiwin'ku cared for primarily by her husband.

As I was refused ethical approval to seek only verbal informed consent from Yolŋu interlocutors, written informed consent was sought. Yinin and Mr Muŋul̲purr assisted me to translate the participant information sheet and consent form into Djambarrpuyŋu, a commonly spoken Yolŋu language and Mr Muŋul̲purr's primary language. We also converted the participant information sheet into a visual flipchart with accompanying text in Djambarrpuyŋu (see Appendix 1 to view informed consent materials). Concepts that required particular attention in the translation process included informed consent, withdrawal from the project, and the risks and benefits of the project. Although some Yolŋu interlocutors expressed appreciation of our efforts to translate the consent materials, it was evident that others had little literacy in English or Yolŋu languages and appeared to experience

embarrassment in being unable to determine which checkboxes to tick or where to sign the form independently. Some elderly interlocutors had poor vision and found the physical act of signing the consent form difficult. I was also required as a condition of ethical approval to discuss with interlocutors their wishes regarding their data should they pass away. Yinin and Mr Muŋul̲purr advised that this could be interpreted by interlocutors as a suggestion that their deaths were impending and may be received as offensive. Despite this, Yinin and Mr Muŋul̲purr recommended some sensitive wording in Djambarrpuyŋu. In response to the question, interlocutors generally expressed a desire for their families to decide on the future use of their data.

I approached health professionals, housing officials and health policymakers through a range of strategies including by drawing on personal and professional contacts, working through intermediaries, approaching people directly (at the renal unit or via email) and adopting a snowballing strategy. Health professionals, housing officials and health policymakers who participated in interviews and observational research all provided written informed consent (see Appendix 1). The health professionals and housing officials I interviewed were all involved in direct 'street level' work with patients or clients. The vast majority of policymakers I interviewed were former clinicians, so their perspectives were likely informed by previous direct patient work, including in remote communities, as well as the habitus of their positions in healthcare systems at the time interviews took place.

Health professionals and housing officials I interviewed have been de-identified and assigned pseudonyms in order to protect them, as public servants, from any possible ramifications for their employment. As many of the health policymakers I interviewed were public figures accustomed to making public statements, I consulted with those I interviewed about the publication of their names in this thesis. All named health policymakers in this thesis provided informed consent to be identified. I have not provided the professions or job titles of de-identified health professionals, housing officials and health policymakers in this thesis as in many cases, doing so would compromise their de-identification. As a result, I am unable to provide a similar table of interlocutors who were involved in my research on account of their professional roles.

Research methods

Research methods primarily comprised participatory observational research and qualitative interviews. Interviews with Yolŋu renal patients and their carers were usually conducted at

interlocutors' homes and living spaces and in public spaces such as parks and reserves. Interviews were generally conducted over a shared meal that I arranged, and were often intertwined with observational research. At other times, observational research was conducted without interviews, when interlocutors invited me to visit them during dialysis, to accompany them during hunting trips or to assist them with accessing social services and with various life projects. I also produced a series of brief documentaries in collaboration with co-researchers and consenting Yolŋu interlocutors and took occasional photographs after obtaining the informed consent of interlocutors. While the primary purpose of documentaries was to communicate the research to Yolŋu interlocutors' families and other Yolŋu, and to a lay Balanda audience, interviews filmed in the course of producing the films also provided a source of data. I was refused ethical approval to collect data from digital inscripts (eg: social media) from consenting interlocutors.

Interviews conducted with renal patients and their carers were semi-structured and unstructured. Some interviews were held with a single renal patient or carer, others with multiple renal patients. Yolŋu interlocutors determined whether others, including co-researchers, carers and other kin, would be present during interviews. They almost always requested the presence of co-researchers, and were often surrounded by close relatives. Generally I developed a list of topics, and sometimes specific questions or wording. At times I also sought co-researchers' advice on how to approach specific issues. Excessive questioning is not a communicative norm for Yolŋu (Harris 1987), so I attempted to raise issues and topics through general discussion and avoided asking too many questions in a single interview. Yolŋu co-researchers were usually present during qualitative interviews and either facilitated or participated in the discussion. Discussions were generally free-flowing, similar to the 'yarning' technique described by Bessarab and Ng'andu (2010), including much socializing, and I was generally willing to allow Yolŋu interlocutors and co-researchers to determine the direction of the conversation. While I initially experimented with audio recording interviews with interlocutors' informed consent, this seemed to transform discussions into performances and so was abandoned in favour of written notes. Interviews were conducted in English, Djambarrpuyŋu and occasionally other Yolŋu languages; and often involved a mix of English and Djambarrpuyŋu. I have a basic proficiency in Djambarrpuyŋu and have completed a Graduate Certificate in Yolŋu Studies. While Yinin and Mr Muŋul̲purr were able to act as interpreters at times when the discussion was beyond my level of comprehension, often their roles as facilitators or participants prohibited this. In circumstances in which I suspected I had missed some important information, I revisited the content of interviews with co-researchers afterwards.

While my positionality and willingness to assist Yolŋu interlocutors with mundane tasks in their daily lives gave me considerable access to information, I could not assume that such information was always shared with me for research purposes. I sought consent for the use of information shared outside of qualitative interviews by raising it during subsequent interviews. I endeavoured to check the information and perspectives shared by Yolŋu interlocutors in interviews by revisiting this content in subsequent interviews, however this was not always possible due to the deaths of several interlocutors.

I completed semi-structured qualitative interviews with 35 health professionals, health policymakers and frontline housing officials in Darwin and north east Arnhem Land, as well as reviewing a broad range of relevant policy documents. Interviews with these professionals were audio recorded and transcribed verbatim using Inqscribe© software. I also recorded contextual information in hand-written notes during interviews, which were later summarised in interview transcript files. Following interviews I sent transcripts to interviewees for checking. I did not seek to conduct observational research with housing officials and health policymakers as they were not my primary cohort of interlocutors and because I assessed that I was unlikely to receive approval for observational research from relevant government departments. I received approval from the Northern Territory Department of Health to conduct limited observational research with consenting health professionals, during their interactions with consenting patients. This was handled by conducting observational research with a small number of health professionals after they had participated in a qualitative interview, where informed consent was obtained for the interview and observational research.

The deaths of Yolŋu interlocutors

Three Yolŋu renal patients with whom I was connected tragically passed away during my fieldwork, including Mr Muŋuḻpurr and another interlocutor. A further three interlocutors have passed away at the time of writing in no less tragic circumstances. Some patient deaths were unexpected, while others were preceded by only a very brief period of deteriorating health. Two patient deaths can be understood as intentional, either through a decision to withdraw from treatment or to end life, both of which were described by patients' close relatives as a response to the social circumstances of life in Darwin.

In all kinds of research, researchers themselves are the instruments of interpretation, bringing the conscious and non-conscious affective dispositions of being human to bear on their projects. In

immersive modes of enquiry, however, I suggest it is impossible (and undesirable) not to experience the suffering of those with whom we work in some way. Perhaps it could be said that emotional or troubling experiences are an occupational hazard of ethnographers. As I stood with Mr Muŋuḻpurr's wife, sisters and perhaps 50 members of the Yolŋu communities of Darwin at the intensive care unit in grief and disbelief while his life support was switched off, I did not consider myself to be conducting 'fieldwork', and was in no state to think analytically. His death and those of other interlocutors, however, have undoubtedly coloured my analysis of the data.

Following each interlocutor death, I sought advice from Yinin about protocols of behaviour and about approaching interlocutors' relatives regarding the publication of their data. Yinin brokered consultations with interlocutors' relatives who held authority over interlocutors' funeral ceremonies and affairs. In some cases, consultations were held a few months after patients' deaths, but in other circumstances, I avoided approaching families during early periods of grief on Yinin's advice. In each instance, I was given permission by interlocutors' families to publish data. Interlocutors' relatives often commented that they supported the objectives of my research. Some advised me to wait for a period of mourning to occur before publishing interlocutors' names or images, or wanted images withheld, which I have respected. I also provided copies of images and footage of deceased interlocutors to their relatives when desired.

The research setting: Darwin

Figure 3 View of Darwin city from Charles Darwin National Park

Credit: Stefanie Puszka

Having described my adoption of a methodology of an ethnography of encounter, I now contextualise my thesis in the research site. In this section I provide an overview of Darwin, the capital of the Northern Territory of Australia and the site of my study. I draw on a range of materials including official statistics, historic records, reports, non-academic literature and my own ethnographic observations in order to provide an account of the town and the ways it may be experienced by interlocutors.

Darwin was first established in 1869 on the country of the Larrakia people, as a port to service pastoral and agricultural industries (Northern Territory Library 2019). It was quickly subject to a gold rush and in the early 20th Century acquired strategic importance as a defence base (Northern Territory Library 2019). Under the regime of Chief Protectors from the early to mid 20th Century, Indigenous people could be compelled to live on missions and reserves, and Darwin at that time was a place of racial segregation (Markus 1990). From 1918 until 1950, all Indigenous residents and visitors in Darwin were prohibited from residing within the town centre. Indigenous people were compelled to live in institutions beyond the town boundaries, initially at the Kahlin Compound and later at Bagot Reserve, where they received meagre sustenance and were trained to perform manual and domestic labour for the settler economy (Wells, S 1995, 2000).

Greater Darwin today encompasses Darwin city and its surrounding suburbs; the satellite city of Palmerston; and the rural areas of Howard Springs, Humpty Doo and Coolalinga (Figure 3). It has a population of 137, 000, 8.7% of whom identify as Aboriginal and/or Torres Strait Islander and 37.3% of whom were born overseas (Australian Bureau of Statistics 2016d). Darwin has a tropical climate featuring a wet season of high humidity, high rainfall and maximum daily temperatures in the mid-30s (degrees centigrade) from October to April; and a dry season of low humidity, low rainfall and maximum daily temperatures in the low-30s from May to September (Bureau of Meteorology 2020). In addition to its Indigenous residents, Darwin contains visible Greek, Chinese, Philippine, Timorese, African and Indian communities. However, geographic segregation is more apparent through class rather than racial distinctions. Town camps, in which some but by no means all Indigenous people live, provide an exception to this. Designated as Indigenous living areas, town camps resemble remote Indigenous communities. They are areas of social housing on crown land, including the Bagot Estate, which exists on the site of the former Bagot Reserve (Day 2007). Town camps are established through a variety of tenure and leasing arrangements and governed to some degree by local elders, through incorporated associations (Fisher 2015).

As Tess Lea (2014) notes, in contemporary times, Darwin is a place of many contradictions and tensions. Darwin offers the affordances of a city, including an international airport, a city centre, bars and restaurants, financial institutions, sporting arenas, two hospitals, shopping malls and the visible presence of Commonwealth, Northern Territory and local governments. Darwin features a substantial number of festivals, public events and weekly markets. Virtually any sport, hobby or pastime is available to Darwinites, including some that perhaps should not be, such as ice skating. Yet Darwin also has a small-town ambiance. As a long-term resident, the occasions on which I leave my apartment without running into someone I know or recognise are rare; and it was also common for Yolŋu interlocutors to be reunited with kin and other acquaintances in chance encounters around the town. While Darwin features a major defence base and functions as a hub for the mining industry, those whose residence in the town pre-dates the previous mining boom suggest that it has become more cosmopolitan; and today Darwin features an array of cafes, boutiques, art galleries and yoga, pilates and cross-fit studios.

In contemporary times, Indigenous people are represented in all facets of Darwin society, but are most visible and most over-represented at its margins. A recent Chief Minister of the Northern Territory was Australia's first Indigenous head of government (Smee & Walsh 2016); and Darwin serves as an unofficial capital of Indigenous culture as the permanent home of the National Indigenous Music Awards and the National Aboriginal and Torres Strait Islander Art Awards. However, Darwin also has a large population of rough sleepers, the vast majority of whom are Indigenous people (Northern Territory Government 2018b). Although the Larrakia continue to struggle to establish native title in Australian law across Greater Darwin and surrounding areas, the Larrakia Nation Aboriginal Corporation acts as a state-like institution in relation to local Indigenous people (Fisher 2015). The Corporation issues non-compulsory identity cards to Indigenous people that are accepted by government and financial institutions and works closely with police, assisting in finding accused offenders and offering a 'sobering up' therapeutic alternative to protective police custody for the intoxicated. It provides a range of social services to Indigenous people from remote communities, including a 'return to country' program. Larrakia Nation may be seen by some Yolŋu as providers of care (Maypilama et al. 2004).

Ben Smee and Christopher Walsh (2016) describe the ethos of the Country Liberal Party, which has governed the Northern Territory for most of the period since self government was established in 1978, as libertarian, pro-small government and anti-Canberra. This ethos could also be broadly attributed to non-Indigenous Territorians and to Darwin itself. The Northern Territory remains the only place in Australia where one can legally purchase fireworks; speed limits for motorised traffic on

major highways have only been imposed relatively recently, and attempts have been made to again abolish them; and residential property is subject to less regulation than interstate (Darwin Community Legal Service & Central Australian Womens Legal Service 2018). Indigenous residents, however, are subject to laws that may criminalise aspects of Indigenous sociality. Indigenous people gathering in groups in public places, including places adjacent to public housing complexes in which many live, may be subjected to police 'move on' powers if members of their group are consuming alcohol (Lea et al. 2012). The public consumption of alcohol in Darwin is permitted in places and at times favoured by non-Indigenous drinkers (Figure 4).

Figure 4 Drinking regulations on the Nightcliff foreshore

Credit: Stefanie Puszka

Darwin is said to be a desirable place for non-Indigenous people from interstate seeking to escape their families or the law (McMillan 1988). While Darwin may also provide a refuge of sorts for some Indigenous people fleeing conflict and violence in remote communities (Holmes & McRae-Williams 2008), the law may be more difficult to evade. Since the Northern Territory Emergency Response, initiated in 2007, town camps have been subject to bans on alcohol and pornography and increased surveillance (Fisher 2015).

Darwin, I suspect, is a place experienced very differently by Indigenous people from remote communities than by the mostly non-Indigenous people tasked with providing healthcare and other services to them. Darwin often figures as a frontier in the imaginations of non-Indigenous people (Lea 2008), who endlessly contrast Darwin to the capitals of other Australian States and Territories from whence many of them come. Amongst Indigenous residents of Darwin originally from remote

communities, however, Darwin may exist as a set of 'city lights' in relation to its remote hinterland. While Indigenous visitors to Darwin, like non-Indigenous visitors and residents, often partake in the city's entertainments, Darwin could also be a dangerous place for some of the Yolŋu I encountered in the town. A series of misfortunes or poor decisions could leave some without a place to stay, without money or food, and stranded, lacking recourse to local elders. It is in this sometimes alluring, sometimes dangerous and marginalising place, that Yolŋu contend with end stage kidney disease.

Limitations

My fieldwork was concentrated in Darwin as this is where Yolŋu renal patients are concentrated, however by restricting my fieldwork to Darwin, I did not encounter patients who refused treatment on diagnosis and opted to remain in their communities and end their lives there. Although no data exist on the numbers of patients in the Northern Territory who refuse treatment on diagnosis of end stage kidney disease, through my discussions with Yolŋu interlocutors and health professionals, I was made aware that some do indeed refuse treatment. I did, however, encounter some patients who decided to end their treatment and hence their lives after commencing dialysis, as noted above. The ethnographic work and the arguments advanced in this thesis therefore only encompass the experiences and narratives of those who decide to pursue treatment, at least initially.

The contrasts I have drawn between Yolŋu care practices and domestic moral economies in Darwin and north east Arnhem Land are reliant on interlocutors' descriptions of lives in their communities and on other published research, but not on my own observational research. Some of the claims that I have made about impacts of urban displacement have thus not been triangulated. Interviews with Centrelink staff would have aided triangulation but requests for interview were refused. To counter potential shortcomings I endeavoured to check facts, claims and perspectives articulated by interlocutors throughout fieldwork though this was not always possible due to the untimely deaths of many Yolŋu renal patients. As a Balanda woman socialised into a Balanda lifeworld through a middle-class upbringing, my capacity to fully understand Yolŋu perspectives was of course also circumscribed. I have indicated throughout this thesis where data may not be well substantiated.

Conclusion

In the Introduction I described my approach to the research problem of the care for Yolŋu renal patients, foregrounding care as a value, relation and set of practices enacted through interactions within families, between health professionals and patients and between citizens and states. In this chapter, I have described my ethnographic approach to understanding the values, relations and practices of care in which Yolŋu renal patients participate, through an ethnography of encounter. Studying Yolŋu relations of care required me to develop relationships with Yolŋu interlocutors myself and to immerse myself in their daily lives, while also raising several ethical issues. I have outlined the ethical issues that arose in this study and how they were addressed. I have also situated my research in Darwin, a place of many contradictions and tensions, and as a place that may be experienced in divergent ways by Yolŋu and by the predominantly non-Indigenous street level bureaucrats and policymakers tasked with providing them with care. In the following chapters I present the outcomes of this approach to the care of Yolŋu renal patients.

Chapter Two

Social and embodied suffering: Yolŋu experiences of end stage kidney disease

Heavy with the weight of swollen limbs and nausea, Bu̲lanydjan was suffering low blood pressure and was barely conscious by the time her plane touched down in Darwin. As nurses from the aeromedical retrieval service transferred her to a waiting ambulance, she began to black out. In her next recollection, staff of the emergency department at Royal Darwin Hospital informed her that she would be transferred to ward seven. Bu̲lanydjan recounted to me, 'I didn't know it was the renal ward'.

Despite her intermittent consciousness at the time, the events leading to Bu̲lanydjan's diagnosis of end stage kidney disease and commencement of dialysis treatment 13 years prior to our first meeting figured firmly in her memory. She recalled first feeling feverish, experiencing swollen limbs and vomiting at her mother's funeral. Relatives massaged her legs and a nurse from the local health centre gave her paracetamol, 'but I was feeling that weakness and tiredness and always sleeping because maybe my kidney was not working properly', she related. Stoically, or perhaps to avoid confronting what her symptoms might indicate, Bu̲lanydjan returned to her job as a pre-school teacher at a homeland she had been living at with her husband. When she travelled to Galiwin'ku for an uncle's funeral, however, health professionals she consulted at the Galiwin'ku health centre conveyed the news of her diagnosis. From Galiwin'ku, Bu̲lanydjan was medically evacuated to Darwin, accompanied by her husband.

On arrival at ward seven, Bu̲lanydjan recognised another patient, a woman she knew from Milingimbi. However, the solace of Bu̲lanydjan's reunion was disrupted by a doctor who informed her that she would be required to live the remainder of her life in Darwin. Bu̲lanydjan recalled, 'I started crying and my husband and that lady we were all crying'.

Bu̲lanydjan relayed the disorientation, confusion and terror of a ruptured biography and a new lifecourse governed by an alien treatment. Fearing and not understanding dialysis, she slipped out of the hospital as nurses were about to commence administering her first treatment. She told me, 'I took all my clothes, my things, put my normal clothes over my nighty and I sneak out and run to Yinin's place, where she was staying with that aunty. She said 'what's wrong with you?' I said 'I'm scared' to Yinin's aunty. I was feeling really hot, I grabbed a hose and had a shower on the chair, all my dress was really wet'.

Bu̲lanydjan subsequently left Yinin's house and wondered through suburban Darwin, but described feeling faint. Her legs buckling in front of a house, Bu̲lanydjan gripped the front fence. The residents, upon noticing her, ran to assist her, washing her and offering to call an ambulance. The family attending to Bu̲lanydjan were Fijian missionaries who her mother had worked for in north east Arnhem Land, and from whom she had acquired a name. Bu̲lanydjan eventually relented and returned to hospital, where she commenced dialysis treatment. Her realisation that 'all the poison on the inside was washed, I feel really fresh now like I'm a normal person' convinced her to persist with life in Darwin.

…….

In Bu̲lanydjan's illness biography, the disorientation, pain, confusion and fear of her displacement to Darwin are palpable. The suffering produced by serious illness and a ruptured lifecourse caused Bu̲lanydjan to initially turn away from treatment. And yet, her recollection of the events leading to her commencement of dialysis treatment also foregrounds the numerous people in Darwin and north east Arnhem Land who provided her with care.

This is not a thesis about kidney disease. This is a thesis about care for and by those who are afflicted by it. Understanding Yolŋu values, expectations and practices of care, however, requires first attending to Yolŋu experiences of illness and suffering. The ways in which illness and suffering are experienced may make possible or foreclose avenues for addressing them.

In this chapter I draw on the ethnographic record and empirical data to describe Yolŋu beliefs, values and practices associated with health that are pertinent to kidney disease; and experiences of end stage kidney disease by patients and their families. I introduce concepts and framings that will be expanded on in subsequent chapters. I argue that for Yolŋu, health is an embodied and social experience; and end stage kidney disease afflicts Yolŋu renal patients as an embodied and social form

of suffering. The physical and social dimensions of end stage kidney disease, of failed kidneys, dialysis treatment and urban displacement, are experienced in intertwined ways. For Yolŋu, end stage kidney disease produces an altered sociality. Yolŋu patients' narratives of end stage kidney disease foreground experiences of physical and social displacement; sedentarisation; altered social roles and social status; and absences of relationality.

In the following sections, I discuss a large body of existing literature exploring the experiences of Indigenous Australians of end stage kidney disease. I discuss the strengths and limitations of existing research and outline my own approach to patients' lived experience of end stage kidney disease, drawing on the concept of social suffering. I go on to contextualise Yolŋu experiences of end stage kidney disease in Yolŋu concepts and practices associated with the human body, blood and health, drawing predominantly from the ethnographic record. I then discuss the embodied and social ways that Yolŋu experience end stage kidney disease. I conclude by considering the implications for the care that Yolŋu with end stage kidney disease require.

Conceptualising the experience of end stage kidney disease

A substantial body of qualitative research has considered the experiences of Indigenous people from across Australia of end stage kidney disease, dialysis and relocation for treatment, predominantly from within the disciplinary framework of public health. Existing studies tend to have similar approaches and findings, closely attending to experiences of displacement and loss and their impact on patients' health and wellbeing. Studies exploring patient experiences of dialysis treatment in urban environments overwhelmingly describe intense feelings of loneliness and isolation and a sense of disconnection from family, country and identity (Anderson, K, Cunningham, et al. 2012; Bennett et al. 1995; Burnette & Kickett 2009a; Devitt & McMasters 1998; Hughes, J et al. 2018; Rivalland 2006; Rix et al. 2014; Rix et al. 2016; Willis 1995). Relocation is said to displace Indigenous patients and their kin from reciprocal relations of care and other social obligations (Anderson, K, Cunningham, et al. 2012; Burnette & Kickett 2009a; Devitt & McMasters 1998; Rix et al. 2014; Willis 1995). These experiences are described as negatively impacting on physical health (Anderson, K, Cunningham, et al. 2012), on personal autonomy and ability or willingness to engage with treatment regimes (Anderson, K, Cunningham, et al. 2012; Burnette & Kickett 2009a, 2009b; Devitt & McMasters 1998; Rivalland 2006; Willis 1995) and on resilience and ability to cope in a foreign environment (Devitt & McMasters 1998; Rix et al. 2014).

Existing studies comprehensively catalogue patients' experiences of displacement and loss. As I will go on to show in this chapter, Yolŋu experiences of end stage kidney disease do not fundamentally differ from the experiences described in these studies. The vast majority of this work, however, draws an implicit distinction between illness experience and the experience of treatment and displacement, and fails to contextualise experiences of end stage kidney disease in Indigenous conceptualisations of the human body, health and care. Much of this literature falls short of describing the broader social and political implications of displacement, although the Central Australian work of Jeannie Devitt and Anthony McMasters (1998) and of Jon Willis (1995) are exceptions. Existing studies tend to attribute Indigenous renal patients fixed and bounded identities and forms of belonging. As refugee and migration studies scholars remind us, assumptions about identity, tradition and culture that contain sedentary biases fail to pay attention to processes of social change and adaptation (Clifford 1992; Malkii 1995). Liisa Malkii (1995) warns against overlooking placement within displacement. The narrow kinds of belonging attributed to patients by many existing studies fix patients as certain kinds of subjects, without enquiring into processes of adaptation and remarkable achievements of survival in conditions of extreme precarity.

In exploring how Yolŋu make sense of end stage kidney disease, I draw on approaches to illness in medical anthropology that connect social and bodily forms of suffering. In the 1980s, Elaine Scarry argued that bodily pain was almost incommunicable, and our inability to fully grasp others' suffering has political implications for societies' capacity to address suffering (Scarry 1985). While Scarry's work has rightly been criticised for its Eurocentric bias and its inattention to social and somatic dimensions of pain, it influenced subsequent directions in medical anthropology and the social sciences more broadly on corporeal dimensions of illness, the embodiment of illness and suffering and bodily agency (van Ommen et al. 2016). The concept of social suffering emerges from these currents and registers the embodied, affective, social, intersubjective and political dimensions of illness experience (Kleinman 1988; Kleinman et al. 1997; Scheper-Hughes 1994). This conceptualisation of suffering moves beyond dichotomies of individual/society, health/social problems, representation/experience, suffering/intervention (Kleinman et al. 1997). This concept holds that suffering cannot be separated from experiences of it (Kleinman 1988; Wilkinson 2006). The concept of social suffering sidesteps Western traditions of pain and suffering as incommunicable processes of interior experience. Wilkinson (2006), while acknowledging that we may never fully grasp others' suffering, argues that such traditions are dangerous, making inhumane acts possible. In describing Yolŋu forms of social suffering associated with kidney disease, I accept Yolŋu beliefs that social phenomena may be experienced as bodily forms of pain, or as enabling or inhibiting agency. I attend closely to interlocutors' experiences and narratives of suffering, which do not separate embodied and social

forms of pain. I contextualise Yolŋu patients' experiences of urban displacement in Yolŋu practices of socio-spatial mobility. I conceptualise patients' experiences of urban displacement as an experience of sedentarisation that leads to an altered sociality among Yolŋu with end stage kidney disease.

In order to attend to social dimensions of illness experience, I also draw on the scholarship of non-liberal and non-Western forms of agency. Since at least the emergence of practice theory and post-structural analysis in the 1970s and 1980s, scholars of agency have abandoned the construct of free will as a fiction disembedded from social, cultural and structural realities, and have examined how society and the possibilities of human action are co-constituted (Ortner 1984). In particular, scholars of agency in non-Western societies have shown how agency may be constituted in ways other than through the empowerment of autonomous individuals (Ferguson, J 2013; Mahmood 2001). Ahern, in her review of concepts of language and agency in anthropology, defines agency as 'the socioculturally mediated capacity to act' (Ahern 2001: 112). While debates about the relationship between intent and agency are less relevant to my analysis, I approach the agency of Yolŋu patients and their families as their capacity to act in ways that are meaningful to them, within the social, cultural, political and economic contexts they inhabit.

Yolŋu conceptualisations of health as an embodied and social experience

Yolŋu interlocutors accentuated experiential and social dimensions of health and illness. Feelings, thoughts, sensations, impulses and sensory perceptions associated with one's body and one's social relations were often emphasised in the ways that Yolŋu interlocutors described their experiences of kidney disease and other ailments, as well as in interlocutors' quotidian small talk. Drawing heavily from the existing ethnographic record, as well as from empirical data, in this section I describe Yolŋu beliefs and practices associated with the body and health which are pertinent to kidney disease. I discuss Yolŋu conceptualisations of clan solidarity and of clans' relationships to country as animated by a sense of shared inner substance or consubstantiality. I describe the Yolŋu concept of *märr*, or one's personal lifeforce, which is nourished through intersubjective connection to kin and country. I discuss Yolŋu practices of socio-spatial mobility and of sorcery, through which social relations are understood to impact on personal vitality and agency.

Consubstantiality between people, and between people and country

Yolŋu express their relationships to kin through their corporeality. Yolŋu hold blood to be sacred, as a representation of patrilineal clan identity and relationality[6]. Dianne explained that each clan has different names for the body and blood. One interlocutor expressed patrilineal and matrilineal forms of relatedness to people and land when he asserted, 'Dad is my blood, Mum is my heart'. Mr Muŋuḻpurr explained to me his intention to seek a kidney transplant from one of his daughters as he did not want foreign blood from a stranger's kidney to enter his body. Kin and clan relationality was constituted through consubstantiality.

Yolŋu also conceptualise their relationships to their country, including land, sea and waterways, as relationships underscored by a shared essence. Yolŋu describe their country as containing the substances and powers of ancestors and the spirits of a group's deceased, unborn and living members (eg: Keen 1995; Magowan 2001b; Morphy, H & Morphy 2006; Tamisari 2014; Williams, N 1986). Yolŋu refer to country in both kinship and bodily terms. Mr Muŋuḻpurr explained to me, 'all places have a family', and interlocutors described their relationships to tracts of land as their country, their mother country and their mother's mother country, making no distinction between their relationships to land and its people. Yolŋu also map the human body onto landscapes lexicographically, for example, through the following terms in Yolŋu languages: *dhakal* (cheek/jaw/fruit/island), *ŋurru* (nose/tip/peninsula/cape/point of a spear/point of a story/clan leader), *makarr* (thigh/tract of land), *ḻuku* (foot/footprint/root/foundation), *mayaŋ* (neck, creek) *dhuḏi* (buttocks, hinterland, base, last) and, significantly, as we will see, *guḻun* (stomach/waterhole) (Charles Darwin University 2014; Keen 1995).

The embodied character of Yolŋu attachments to country is further illustrated in funeral ceremonies, in which a deceased person's spirit is transported to their clan's sacred waterhole. Ceremonial performances of particular songs and dances narrate the deceased person's affiliations with particular clans and country, sending their spirit on its sacred journey. According to one interlocutor, funeral ceremonies were also held for the amputated limbs of people with diabetes. As with ceremonies for deceased people, ceremonies were required for amputated limbs to prevent their amputation from social and topographic networks. Yolŋu inhabit a corporeality which is at least partially collective and topographic, through which individuals locate parts of themselves in others and in country.

[6] Yolŋu have gender-based taboos associated with blood and associate it with sacred knowledge, so I avoided asking questions or probing understandings of blood with interlocutors too deeply, especially men, and mostly relied on the knowledge of blood that interlocutors volunteered of their own accord.

Consubstantiality between Yolŋu and their country animates interdependencies of mutual nurturance. Ian Keen (1995) describes significant sites for Yolŋu as places that at once figure strongly in stories about ancestral journeys and as present-day resources; and also discusses the responsibilities of people to safeguard objects, ceremonies, designs and knowledge associated with such sites. Fiona Magowan (2001a) describes the intertwining Yolŋu customary and Christian spirituality in experiences of being 'in place' through presence on particular country in the company of particular kin. Feeling 'in place', according to Magowan, invokes shared emotions and feelings.

Life-giving interdependencies among Yolŋu and between Yolŋu and country acquire a densely networked character. Long-running debates amongst anthropologists about the nature of Yolŋu social organisation illustrate a density of non-hierarchical connections between individuals, collectivities and country forged through actual and classificatory kinship, common ancestors, languages, ceremonies, designs and clan and familial alliances (eg: Berndt 1976; Keen 1995; Warner 1937; Williams, N 1986). When asked where they were from, interlocutors tended to nominate a single community or homeland; however, further discussion about their biographies usually elucidated several places across north east Arnhem Land that could be called 'home' or in which they had lived for periods of time. Yolŋu interlocutors were often able to describe relationships to other Yolŋu who were not immediate kin in multiple ways, for example, as both classificatory kin and as people who related to one another through the relationship between their clans; or through both matrilineal and patrilineal connections. Frances Morphy (2007b, 2010) depicts Yolŋu social geographies as 'nodal networks' that connect nodal places and individuals through non-hierarchical grids. Nodal networks incorporate significant sites and settlements associated with patrilineal clan estates and other centres of identity, and also integrate connections to other people, collectivities and places.

Yolŋu derive strength from social geographies of nodal networks between kin and country. Yolŋu often represent processes of extending their networks to generate new connections and produce new knowledge as the mixing of salt and fresh waters, while the still waters of sacred waterholes represent each clan's endowment (Marika et al. 2009; Marika-Mununggiritj 1991; Stewart & Strathern 2001). When visiting Yolŋu homelands, on several occasions, landowners have welcomed me to significant sites in which fresh water can be seen bubbling up in the midst of mangroves, or at sandy beaches at low tide. On one occasion, one of my hosts described qualities of a place in which a fresh water spring flowed into salt water, which she said was 'making me feel connections, giving me strength'.

Märr: Personal vitality and power through nodal networks

Through *märr,* Yolŋu derive vitality and power from nodal networks of people and country. *Märr* can be understood as one's lifeforce, physical vitality or agency. *Märr* may reside in and beyond individual bodies. Yinin explained, 'märr… it's in your inner being. You need to have that märr to be able to strengthen you, so you can see yourself out there and lighten you up'. Yinin described *märr* as being particular to individuals or family groups, and associated with physical and immaterial centres of Yolŋu identity, continuing, 'that märr, that märr sits with the family, the land, the people. The language, the memories, the inner being, the sights, the smells, märr is all there back home at our country'. While *märr* can be experienced in other places with which Yolŋu have established personal connections or networks, it is especially efficacious in centres of identity, or nodes. Yinin elaborated, 'if you ask us to go to Melbourne – I've got no märr'. She described deriving *märr* from personal connections and events in Darwin due to her long-standing ties with the town 'because this place Australia is Yolŋu place but only places travelled (have märr)'[7]. However, she added, 'there is a different märr in communities, it's more powerful'.

Dianne and Yinin explained that *märr* resided in humans in the *guḻun* (stomach) and *ŋayaŋu* (inner being). As noted earlier, the term *guḻun* could also refer to waterholes, and particular waterholes were considered to be spiritual reservoirs and centres of identity for particular clans. *Märr* becomes embodied in people through sensory experience, according to Yinin:

> (Renal patients) *want to be where, they want to be at the beach, to feel this wind. To feel the breeze... Feel the breeze and listen to the land. Everything, whatever the land holds. That's where the märr is for the Yolŋu people. Then they can see their life, their journey through the land. To be able to connect with the märr.*
>
> *…But I've seen, I've come across many, many times back home at community, renal patients, they sit or they sleep next to the campfire, people making noise, that's what they want! That's what they wanna hear! That's who they were before! They want to listen to the children playing, people talking, not being isolated. That's it. Yes. Sit with people under the big, like at Galiwin'ku, that big tree. Just sitting there, looking at each other, asking, saying this, doing that, running over there, who's coming, what are they doing, that's it.*

Märr is thus constituted among Yolŋu through social action.

Based on fieldwork conducted in north east Arnhem Land in the 1930s and 1940s, Donald Thomson (1949, 1975) described *märr* as a 'spiritual power' that was primarily invested in sacred objects (*raŋga*). *Märr*, according to Thomson, was not invested in people but could have a powerful influence

[7] Interlocutors sometimes referred to all Indigenous Australians as 'Yolŋu'.

on behaviour. *Märr* could not be seen but was felt through the revelation of *raŋga* during men's ceremonies, creating an intense solidarity amongst ceremony participants. The *märr* invested in *raŋga* conferred prestige, social status and luck in hunting to initiated men, but could be dangerous to women and children, causing illness. *Märr* was also experienced during ceremonial exchange by men who successfully executed obligations to give, receive and repay gifts; and in secular forms of gifting, such as the gifts of food a man might bestow on a potential mother in law, which were said to be motivated by goodwill and designed to leave an impression of obligation. Thomson suggests that *märr* can be understood as a sensibility or motivation that produces social value. Interlocutors did not describe sacred associations or dangerous dimensions of *märr* in discussions with me, however Yolŋu concepts often have 'inside' meanings that are not made public (Deger 2016), and it is possible that they may have refrained from discussing dimensions of *märr* associated with taboo or sacred topics with me.

Michael Christie and John Greatorex (2004) contend that in contemporary times, Yolŋu conceptualise *märr* as residing in people, where previously it was conceptualised by Yolŋu in a more boundless way. They describe *märr* as a personal attribute of power through the strength of one's identity and social connections. Interlocutors articulated similar conceptualisations, in which it was possible for people, such as renal patients, to have insufficient *märr*, and this could manifest in physical weakness and passivity, as will be discussed further below. Franca Tamisari (2014) further expounds *märr* as a personal quality that is felt in relation to one's relationships to relatives and country, encompassing both knowledge and experience, and which denotes that which 'makes things happen'.

The strength and vitality derived from *märr* were described by interlocutors as enabling one to act on the world and embody a moral subjectivity. Yinin described a person nourished by *märr* as embodying qualities of 'generosity' and 'a good heart'. She explained, 'being with people, thinking the right way – (one's) inner being is good'. Dianne similarly described *märr* as enabling one to 'think the right way, go along the right path'. Conversely, the negative morality of disrespecting *rom* (law, rules or norms), and hence disrespecting elders, caused 'old people (to) lose value, märr', according to Dianne. Fiona Magowan (2001a) has similarly argued that for Yolŋu, seeing and feeling provides impetus for acting. Victoria Burbank, meanwhile, argues that for her southern Arnhem Land interlocutors, feeling and embodying the point of something, rather than merely understanding it, provides a legitimate motivation for action; and desires to feel and embody courses of action could bring her interlocutors into conflict with Western institutions of work and education (Burbank 2006). Yinin's narrative suggests that *märr* may be understood as providing a capacity for reflexivity or consciousness. She

describes *märr* as enabling one to 'see yourself out there', permitting Yolŋu to 'see their life, their journey through the land'.

Practices of mobility: connecting people and country, enacting power and agency

Yolŋu communities are characterised by high levels of temporary mobility between dwellings and at a regional level (Morphy, F 2007b, 2010). While the physical mobility of Yolŋu renal patients was constrained by the demands of their treatment, as will be discussed further below, renal patients tended to attract large numbers of visitors who appeared to stay for varying lengths of time, from a few weeks to several months. It was also common for renal patients' relatives who were more permanently residing in Darwin to return to north east Arnhem Land to visit other relatives or attend events, for periods of weeks or months.

Through practices of mobility, Yolŋu derive strength from relationships to kin and country. A body of literature describes Indigenous practices of temporary socio-spatial mobility between houses and on a regional basis, across Australia (Dockery, A & Colquhoun 2012; Memmott et al. 2006; Musharbash 2008; Prout 2008; Taylor 1989; Young & Doohan 1989). According to this literature, temporary mobility patterns may be shaped by desires and responsibilities to visit kin and country, the availability of hunted and gathered resources, employment opportunities in the formal economy and state institutions and services. Indigenous scholar Jenine Godwin Thompson (2014) describes such practices as enactments of Indigenous conceptualisations of health and integral to the maintenance of relationships with kin and country. Practices of temporary physical mobility are critical to the enactment of Yolŋu nodal networks (Morphy, F 2007b, 2010) and, as my interlocutors illustrate, to the capacity of Yolŋu to derive strength and vitality from *märr*.

Similarly to the representation of *märr*, it was common for Yolŋu to express physical mobility as the enactment of personal agency or capability. Interlocutors on multiple occasions contrasted *rom* (laws, rules, norms), which was said to be lying, or stood in, and fixed, with *dhukarr* (pathways), which had the potential to be created agentively. Yinin explained that doctors must follow the *rom* of medical guidelines, but must find a *dhukarr* with patients to explain the *rom*. In a documentary about the late Yolŋu recording artist and renal patient, Dr G Yunupiŋu, one of the artist's uncles described the artist's early life as a blind man who 'wouldn't show his independence, move around from place to place', until he became an established musician (Williams, P 2017). *Malŋ'maram dhunupa dhukarr* (finding the right or straight pathway) was a phrase sometimes used by Yolŋu, expressing a moral subjectivity.

Yolŋu practices of physical mobility are thus connected to the ways in which Yolŋu are constituted as social and moral beings. While Talal Asad (2000) locates agency in the human body and in its capacity to experience pain, Yolŋu exercise a relational form of agency located in relationships among kin and between people and country, which can be enacted through practices of physical mobility.

Social conflict and sorcery

Yolŋu conceptualise illness, as well as health, as constituted through social action. Yolŋu attribute some physical and psychological illnesses and accidents to sorcery attacks. A sorcerer (*galka)* is said to exercise external control over victims and to inflict illness and suffering by tampering with victims' blood and other bodily excretions (Reid 1983). While sorcery constitutes a taboo topic, and was not one that I specifically sought to explore, interlocutors sometimes spoke to me about accusations and rumours in hushed tones. While some attempted to prevent accusations and rumours from spreading, none denied their beliefs in the efficacy of sorcery attacks. Both Janice Reid (1983) and John Cawte (1996) argue that Yolŋu practices and accusations of sorcery represent social or political conflict, often associated with extra-marital affairs, social misconduct and conflict between clans. Clan groups have corporate liability for the conduct of their members, and a *galka* may miss their target and instead inflict the intended victim's kin. Sorcery accusations may be strategies for expressing loyalties or protecting interests in inter-clan affairs. Reid (1983) also argued that the social stress for Yolŋu of living in sedentary, multi-clan communities and crowded housing has precipitated an escalation of sorcery. Victoria Burbank, based on fieldwork in southern Arnhem Land, further illustrates how the capacity for sorcery to cause physical illness is intelligible in biomedical terms through the causal pathway of chronic bodily and psychological stress; and premature morbidity and mortality may lead to further stress (Burbank 2017).

The collective and social nature of Yolŋu corporeality further discredits Scarry's (1985) contention that the near-incommunicability of pain and illness is universal. For Yolŋu, a corporeality that is social and topographic suggests that pain and illness are likely to be intersubjective experiences that may transcend linguistic communication. Furthermore, a relational form of personal agency among Yolŋu, arising from the embodiment of a shared essence, suggests that the social conditions of treatment, including the displacement that Yolŋu renal patients contend with, impact on bodily dimensions of illness and on Yolŋu responses to it.

End stage kidney disease as an experience of embodied and social suffering

In the previous section I argued that Yolŋu conceptualisations of health and illness transcend categories of the physical, social, moral and political. In foregrounding experiential dimensions of health and illness, interlocutors often adopted a pragmatic approach to seeking biomedical and customary forms of treatment, based on their availability and experiences of the efficacy. Anthropologists of Yolŋu society describe syncretic beliefs and practices associated with health and the human body amongst Yolŋu that may combine customary, biomedical and Christian explanatory models of disease and forms of treatment (Cawte 1996; Magowan 2001a; Reid 1983). Amongst Yolŋu renal patients, dialysis treatment that relieved pain and discomfort could be assimilated into experiential conceptualisations of health and treatment. Dialysis treatment provided through urban displacement, however, was said to minimally sustain patients without making them well. In this section, I describe how end stage kidney disease and displacement were experienced by Yolŋu interlocutors as an embodied and social form of suffering. I show that Yolŋu patients' narratives of end stage kidney disease foregrounded experiences of physical and social displacement; sedentarisation; altered social roles and social status; and absences of relationality.

Physical and social displacement

For Yolŋu, end stage kidney disease and a hub and spoke model of dialysis gave rise to displacement within the Australian state. Relocating to Darwin implies a physical journey of around 500 – 1000kms or more, complicated by the expense of air travel, poor roads and the inaccessibility of land-based transport to many parts of Arnhem Land in the wet season. Being diagnosed with a serious illness while concurrently becoming separated from centres of identity presented an extreme form of biographical disruption, as Bu<u>l</u>anydjan's opening narrative demonstrates. The embodied and social suffering of kidney disease and displacement were indissoluble in interlocutors' narratives.

For Yolŋu interlocutors, displacement was experienced in social and bodily ways. Some described feeling out of place, referring to themselves as 'foreigners' or 'refugees' in Darwin, as people belonging elsewhere. Yinin lamented, 'it is hard to see family going through this process. Getting treatment somewhere that we don't belong. It's foreign altogether to Yolŋu people, living here and not going back home to be with the family'. One interlocutor relayed her attempts to seek assistance from an organisation providing services to migrants and refugees, where she pleaded with staff, 'I'm

refugee too, I'm a longgrasser[8]. You think overseas mob are refugee only, Aboriginal people are refugees too'. Mr Muŋul̲purr and Waymamba described the sorrow of their displacement from consubstantial relations with kin and country as an experience of bodily and social cleaving in the following exchange:

> Mr Muŋul̲purr: *Family is like, like it's a country when someone gets that land and at the same time it's pulling you, one part of your body, it's pulling it out.*
>
> Waymamba: *It's pulling out one piece attached to the body, that's how we feel.*
>
> Mr Muŋul̲purr: *It's the same, family's like country, see. Life, sea, songlines. Same like human family, spirit it nurture us.*
>
> Waymamba: *your body is connected to the land, your family.*
>
> Mr Muŋul̲purr: *your mother land.*
>
> Waymamba: *your mother land, your land, your songline, is connected, it's missing because we are here* (Darwin)*, separating our body from our land, and we are isolated from it.*
>
> Mr Muŋul̲purr: *when we living here our soul and our mind is back there with those people we love.*

For Mr Muŋul̲purr and Waymamba, displacement was animated not only by emotions of loss and grief, but also by bodily sensations of separation.

Interlocutors discussed the social suffering produced by displacement and immobilisation as being embodied in similar ways to the physical symptoms of end stage kidney disease. Mr Muŋul̲purr described feeling 'shame' regarding his inability to attend a relative's funeral as a result of immobilisation in Darwin. Concepts of 'shame' as used in Aboriginal English may express transgression of social norms, failure to show respect and social isolation (Harkins 1996; Kwok 2005, 2012). He told me, 'shame goes all the way through the body. It creates stress and toxins build up'. Mr Muŋul̲purr described 'loneliness' as another form of suffering that 'builds up', leading to the immobilisation of patients in wheelchairs, mirroring the language of healthcare, of patients who acquired too much fluid in their bodies. Another interlocutor, echoing health professionals who warned patients against overloading their bodies with liquids that they were unable to expel, described her mother, a renal patient, as 'overloaded with worries'.

[8] This is a local term for homeless people. It refers to speargrass that grows to over two metres tall during the wet season months and reflects attempts amongst homeless people to camp away from the surveillance of authorities (Day 2000). The term is commonly used amongst Indigenous people in Darwin, as well as amongst service providers and local authorities.

It was common for Yolŋu to express end stage kidney disease as 'poison in the blood'. I argue that this representation intertwines biomedical and customary explanatory models of disease. Representations of 'poison in the blood' were not entirely disconnected from biomedical explanatory models of end stage kidney disease, in which waste and fluid accumulate in the body between dialysis sessions or in the absence of treatment[9]; but where medical discourse accentuates non-functioning kidneys and bodily homeostasis, Yolŋu emphasised the ways in which end stage kidney disease was experienced. As Kleinman (1988) asserts, symptoms endow illness with meaning. Representations of end stage kidney disease as 'poison in the blood' at once expressed embodied symptoms and offered a social explanation, of altered relationships among kin and between people and country, drawing on cultural representations of blood as relationality. Another interlocutor, the daughter of a renal patient who had passed away in the preceding years, recalled her mother likening dialysis to the process of making cycad nut (*warraga*) bread, which she described as a 'sacred food'. Poison is leached from the nuts, which are subsequently ground into a paste, mixed with water to form dough and baked on a fire. Through immobilisation and disconnection from centres of identity, I argue representations of 'poison in the blood' expressed severed relations to kin and country.

Sedentarisation

Bu<u>l</u>anydjan's narrative foregrounds the loss, disorientation, pain, confusion and fear of displacement to Darwin. Other interlocutors gave similar narratives of the people and events associated with their diagnosis, and of the liminality of relocation and commencement patienthood, which were often unprompted by me, and frequently recalled many details of events many years prior. Displacement to Darwin and the commencement of dialysis were evidently traumatic and life-changing events for many patients. And yet, Bu<u>l</u>anydjan's story also illustrated her network of relations in Darwin. In the following, I illustrate how the sedentarisation of Yolŋu renal patients in Darwin shaped their experiences of displacement, displacing them from a form of sociality that required physical mobility.

Yolŋu have well established associations with the place now known as Darwin (Christie & Greatorex 2004; Maypilama et al. 2004). Interlocutors described relationships between Yolŋu and Larrakia pre-dating colonisation. Ŋarritj discussed his forbears' connections to the Larrakia and other Indigenous societies across what is now known as the Top End of the Northern Territory, telling me, 'our ancestors used to travel all the way from Arnhem Land to Port Keats, for ceremony. We've got

[9] In biomedical understandings, end stage kidney disease does not imply sepsis (blood poisoning), although the two conditions can be related (Shen et al. 2014; Wong, J et al. 2014).

songlines in common'. Young Yolŋu men took up work in Darwin in construction and shipping industries in the 1930s in exchange for rations (Maypilama et al. 2004). Mr Muŋuḻpurr related his father's residence in the town during World War II, when he worked at the air force base. In contemporary times, well-established but transient and spatially dispersed Yolŋu communities persist in Darwin, and their presence likely reflects, in part, hub and spoke models of service provision centred in the town (Christie & Greatorex 2004; Coulehan 1995; Maypilama et al. 2004; cf Prout 2008). Several Yolŋu organisations and businesses employing Yolŋu and Balanda[10] staff have offices in the town, and Yolŋu Radio is broadcast to Darwin residents, as well as in north east Arnhem Land. Some younger and middle aged interlocutors had attended Darwin boarding schools in their youth. While Darwin is not a centre of Yolŋu identity associated with customary ownership of land, neither is it a foreign location.

While Darwin may form a node in Yolŋu relational networks, renal patients confined to the town were likely to find themselves encompassed in an altered sociality. Patients were often accompanied in Darwin by carers and other close relatives, and generally had other more distant kin also were also resident in the town, as the following chapter will explore. However, the domestic milieu of renal patients in Darwin generally lacked the same quality of the homes they had left in north east Arnhem Land, of large, co-resident extended families, and of neighbourhoods in which every resident was known and could be located in classificatory kin networks. Renal patients who described themselves as 'foreigners' and 'refugees' experienced displacement from country and from a particular kind of sociality.

Renal patients could experience further sedentarisation through aspects of their conditions that could confine them indoors. Patients, whose immune systems were compromised, were advised to avoid going outdoors after heavy downpours during the wet season in order to reduce the risk of contracting bacterial water-borne infections such as melioidosis (Majoni et al. 2018). Some also remained indoors during hot weather to stay cool or to avoid shortness of breath, expressed by patients as 'short wind'. Haemodialysis patients generally have low urine output and are advised to adhere to fluid restrictions in order to avoid fluid build-up between dialysis treatments which can lead to shortness of breath, headaches, abdominal bloating, hypertension, heart failure and swelling (Wong, M et al. 2017). Staying indoors was a strategy adopted by some to manage their thirst. Buḻanydjan detested being left 'alone to sit there and watch all the four corners in the room'. Renal patients experienced their sedentarisation in physical and social ways.

[10] A term used by Yolŋu to denote Caucasian or non-Indigenous people.

Renal patients were displaced from a form of sociality that required physical mobility. Patients often referred to dialysis as a 'one way ticket'. Although most patients were unable to access treatment in north east Arnhem Land communities, health professionals sometimes rescheduled patients' dialysis so that patients could return to their communities for a few days between treatments. However, road-based transport was too time consuming to undertake between treatments and patients often lacked the financial means to pay for flights. Bone disease and frailty are complications of end stage kidney disease (Thomas, R et al. 2008), and it was common for renal patients to become physically immobilised in wheelchairs or to require walkers, further complicating their ability to travel on planes and to airports in remote communities that lacked facilities to accommodate them. Wapiriny explained to me that patients' relatives living in north east Arnhem Land, who made occasional trips to Darwin, sometimes didn't understand the burden of immobility: 'They don't know what it's like to live here in Darwin, they come to do shopping and then go, but living here for 4 or 5 years, it's boring'. For Wapiriny, an immobile life was evidently monotonous.

In Yolŋu nodal networks, mobility is not only an instrument of sustaining networks of relationality; it can be a resource for managing competing responsibilities and diffusing conflict. The Yolŋu scholar Elaine Maypilama and her collaborators describe Yolŋu practices of moving away from a site of interpersonal conflict, to another house or settlement (Maypilama et al. 2004). Far from being abstracted from social relations, patients often complained of the social pressures in Darwin, in which their autonomy was curtailed through immobility. Making a distinction between being separated from close relatives while being surrounded by more distant ones, Mr Muŋul̲purr explained, 'you can't get away from family, family is here all the time to humbug. Hard for house, hard to keep money, hard to bring your family'. In a discussion about problems encountered by renal patients living in public housing with large numbers of visiting relatives, Wapiriny described patients' difficulties in managing social relations in even more stark terms: 'back home there are no problems, family's your enemy here'. As will be argued in later chapters, conflict within the families of renal patients in Darwin could also be a product of the ways in which everyday life was governed through health and social policy in urban areas, which took on different forms to health and social policy in remote communities.

For Yolŋu, sedentary life could be experienced as a form of displacement. One interlocutor lamented, 'we are hooked up here with an anchor and can't take that anchor with us, too heavy. It makes your life homeless'. Waymamba described immobility as causing sickness, recalling conceptualisations of strength and vitality, through *märr*, as the quality of one's networks of people and places. 'We get sick buying food from the shop and from staying on one country all the time', she told me. Displacement did not only mean being in the wrong place, or an absence of belonging. Paradoxically, a sedentary life

lived in the capital of the Northern Territory could attenuate some nodal networks. It could also reify renal patients' networks within the town, to carers, other kin and other associates. As will be explored in more detail in the following chapters, kidney disease and sedentarisation impacted on responsibilities and reciprocities within families in many ways.

Altered social roles and social status

For Yolŋu, end stage kidney disease and sedentarisation implied ruptured lifecourses and social roles. Heil and Macdonald (2008) described Wiradjuri who endured lengthy hospital admissions as experiencing a social death. Although displacement and sedentarisation did not appear to impact on patients' status as elders within their families, which will be discussed in the following chapter, displacement through sedentarisation could prevent patients from performing a range of valued roles within their communities. It could mean missing critical events such as funerals and other ceremonies. It could mean being unable to care for and teach children and grandchildren. It required interlocutors to resign from employment positions within the formal economies of remote communities, from positions as community council members and from roles as coaches of sporting teams. Renal patients often described themselves as 'different from other people', although purporting to be a 'normal person', as Bu̲lanydjan did, could be an intentional act of forgetting their displacement. Renal patients' inability to perform social roles during funerals in their communities in particular could alter their social status.

Funeral ceremonies are important events punctuating the lives of Yolŋu (Morphy, F & Morphy 2012). Some of my interlocutors travelled long distances to attend ceremonies that were held for a week's duration or more. Considerable expense and effort was spent in funerals that I attended in constructing shelters to house coffins during ceremonies and adorning the coffins and shelters with designs, images, flags and colours associated with clans that the deceased was connected to. Like Bu̲lanydjan, several patients' diagnosis narratives were associated with attendance at funerals. Ceremonies are events in which grief is publicly expressed, but also processes of renewal, conciliation and social reproduction. In funeral ceremonies, connections between people and land are enacted through performances of ancestral journeys, which transport the deceased person's soul back to sites on their clan's country (Barber 2008; Morphy, H 1995; Tamisari 2014). Mr Muŋu̲lpurr and Yinin described the intense solidarity of funeral ceremonies that could surpass participants' grief:

Mr Muŋu̲lpurr: *Funerals are the most happiest time for Yolŋu people ever.*

> Yinin: *We want to be like that, sit like that, no matter what we are.*
>
> Mr Muŋuḻpurr: *No matter what tribe.*
>
> Yinin: *We feel free, overwhelmed, connected. There is no sickness, thinking negative, bad thoughts go away.*
>
> Mr Muŋuḻpurr: *This tribe and this tribe had trouble, every time when this bin happen all the spears bin thrown, hide away.*

In funeral ceremonies, value translations are performed from one world to the next, and between generations. According to Franca Tamisari (2014), the distribution of rights and obligations amongst Yolŋu must be felt and performed ceremonially; *rom* (Yolŋu law) cannot be enacted in the absence of performativity.

Renal patients described missing relatives' funerals as one of the most painful aspects of social displacement. Renal patients' inability to attend funerals not only implied absences from performances of family solidarity and law. For older patients, missing funerals could lead to a loss of status as clan or ceremonial leaders. Mr Muŋuḻpurr described the painfulness of end stage kidney disease in the following terms:

> *When we get this sickness we feel like we nobody. That's how we feel. Like we bin let down. We lose everything. We lose family, we lose the good time, we lose friends, we lose future. That's what this sickness does…*
>
> *I look at myself, I say I was not like this before. I was huge big man. I used to work for community police for four years. I used to go hunting every day, on the weekend fishing, spearing, but this sickness bin slow me down. I used to be a tribal leader for the Djambarrpuyŋu clan, I used to lead them but not anymore, because this sickness shut down my future. Shut down the main transfer.*

Renal patients' loss of social status in Darwin could also reflect their encapsulation in a broader, predominantly non-Indigenous society and the governance structures in the town. While some patients were respected in their communities as clan and ceremonial leaders, including by local service providers, in Darwin they were susceptible to pity as vulnerable and often aging people; and, as Chapter Five and Six argue, through social policy, were attributed the status of unproductive labour dependent on the state.

The loss of leaders and elders from their communities could also have broader ramifications for Yolŋu society. Yiŋiya Guyula was an independent Yolŋu Member of the Northern Territory Parliament, who had been campaigning for better access to renal services in his Arnhem Land electorate and caring for his mother's brother who was receiving dialysis in Darwin. He explained that elders' knowledge

needed to be enacted on country in order to be sustained, telling me that 'when people are separated from their country, knowledge starts to grow cold spiritually'. Yiŋiya, like other interlocutors, was also concerned about children in communities being 'undisciplined' in the absence of their elders. As Chapter Seven will further explore, the displacement of substantial numbers of renal patients to Darwin could pose broader threats of dispossession of knowledge and law.

Absences of relationality

Annie sat slumped in her chair, gazing at the floor, occasionally rubbing her forehead as Teresa attempted to discuss her dialysis treatment regime and Annie's propensity to miss appointments, impressing on her the importance of patients being 'stable'. Teresa's voice and presence filled the tiny office on the 7th floor of the hospital. She asked Annie if she was drinking alcohol but Annie denied it, so Teresa moved on to Annie's tea drinking habits, explaining 'that's why you get that build up (of fluid)'. With each question, Annie's head sank further into her hands and she became less and less expressive, giving only a quietly spoken 'yes' or 'no', and eventually not responding to the questions at all. Prior to the meeting, Annie had expressed reluctance in asking health professionals and other street level bureaucrats for help, admitting to me that 'it's really hard for me to ask, I feel hurt'. On another occasion she discussed her propensity to spend large amounts of time alone, in or around the hospital: 'I've got no visitors to visit me in hospital, nobody's there. That's why I sit by myself because my family are back at home… it makes me getting weak'.

Unlike Annie, who had been undertaking dialysis for less than a year, Bulanydjan was well versed in the systems and processes of dialysis, and had no doubt encountered a gamut of different health professionals throughout her 13 years of dialysis treatment in Darwin. Over the course of my fieldwork, I met Bulanydjan in a variety of contexts. At our first meeting, at Bulanydjan's home in the Darwin suburbs in which we established our fictive kin relationship as *momo – gaminyarr* (father's mother – son's child), we talked for over two hours and Bulanydjan seemed to enjoy narrating her biography. Bulanydjan was similarly articulate and animated when I subsequently visited her at her home and met her at picnic lunches with other renal patients and their families at various Darwin beaches, to the extent that others present sometimes complained that it was difficult to get a word in. At the Nightcliff Renal Unit, Bulanydjan was accustomed to instructing staff about how to lift her out of her wheelchair and into a dialysis chair using a device known as a 'sling'. However, when I ran into Bulanydjan at the hospital one day, where we had both attended a viewing of one of Bulanydjan and other interlocutors' close relatives who had recently passed away from a stroke, Bulanydjan seemed

out of character. Bu<u>l</u>anydjan's niece, one of her carers, made arrangements with staff for her transportation to the viewing area down a flight of stairs without her involvement as she sat passively in her wheelchair with a blank expression.

…….

It was common for patients who were acutely unwell or undergoing personal crises, including those coming to terms with their diagnosis of end stage kidney disease and living out the rest of their lives in Darwin, to present in similar ways to Annie and Bu<u>l</u>anydjan. Patients could be inexpressive and listless, ceasing communication or only providing minimal responses to questions, as though they had become shut off from social relations. Ethnographic work conducted with Indigenous people in other parts of the Northern Territory shows that the incommunicative presentation of some Indigenous patients at healthcare services is widespread (Saethre 2013; Senior & Chenhall 2013). Health professionals who I spoke to described to me some of the difficulties they encountered in caring for patients who were incommunicative. Health professionals related two instances to me in which staff considered assessing patients for guardianship, only to realise that patients' lack of participation in their healthcare was not attributable to deficient cognitive function. While relational forms of Indigenous personhood were discussed in the Introduction, here I argue that displacement, which could impact on the social roles and social status of patients, could be experienced as a loss of their personal substance.
Renal patients could experience end stage kidney disease a loss of agency. Recalling Yolŋu constructions of agentive action as mobility and the making of pathways, Yinin explained that processes of displacement and sedentarisation stripped patients of their agency:

> *Once you get sick, once we get sick there's another pathway turning, this way. Most of the time you are here* (at the former, right path). *Here, maybe once. This pathway is finished, done. There's no more pathway, nothing. Your track is off, getting off the track. Only small track, not the big track.*

Dianne complained of experiencing the absence of wind passing through her body in Darwin, depriving her of motivation and purpose. Although winds and sea breezes are present in Darwin at most times of the year, I understood her comment to refer to her inability to experience or derive strength from them.

Care in the absence of relationality did not promote patients' agency. According to Yinin, the *märr* of renal patients receiving treatment in Darwin was no longer cared for through intersubjective connection, but minimally sustained by dialysis machines and unknown health professionals:

> (Renal patients') *only märr is a dialysis machine, it gives märr back. The doctor has a different märr, has a märr that the patient doesn't know – the doctor and the machine… When people get sick, they come here with someone else's märr. Like the machine, or the dialysis machine, that märr. Yes. So their märr and the dialysis machine is connected through the tubes, those räki* (connections)*, like that. Once they leave the tubes, the machine, that dialysis, once they take it out, there is a little bit of märr there but not for long. That's it. It's gonna take them maybe couple of hours and then they go back again, no märr.*

Patients became 'disempowered' through receiving treatment from health professionals and machines which they had 'no connection' to, she explained. 'They meet other, lotta people you don't know. They're thinking, will they help me? They think this is pushing me way too far, discussing their sickness with people they don't know', she added. The passive presentation of some patients was attributed by Yinin and Mr Muŋul̲purr to healthcare devoid of the kin relationality that sustained patients.

Mr Muŋul̲purr and Yinin both agreed that diminished *märr* and being cared for by strangers could lead some patients to miss or cease treatment. Mr Muŋul̲purr explained, 'their soul inside gets shame. They knock back everything'. Yinin commented,

> *And then sometimes that person, they're shutting down. 'I am shame', some people say, 'I am going* (to cease treatment)*'. It's not because they are tired, not because they are sick, too sick to talk to, or it's not because they don't want to talk or don't know anything about it, it's because of the märr. The underlying reason is because of the märr…. some are weak, and cannot talk, shy, shy. They are shy because they don't see themselves who they really are because of their inner being is gone.*

For some, the conditions of treatment and care in Darwin are evidently intolerable. Approximately 17% of dialysis patient deaths in the Northern Territory are attributable to withdrawal from treatment (Australia and New Zealand Dialysis and Transplant Registry 2018). A further uncounted proportion of people with end stage kidney disease decline treatment on diagnosis.

In Yolŋu conceptualisations of embodied vitality, through *märr,* agency is a product of relations among kin, and between Yolŋu and country. Displacement, sedentarisation and altered kin relations could entail extreme losses of personhood and personal capacity. Yinin explained that the foreign, weaker märr that patients embodied through displacement and immobilisation led to them 'fading, drifting away… because they know, they know that their body is going to change later on. In two or three years' time they will change eventually. They will not be the same people'. Yolŋu renal patients, whose identity and personal strength were a product of nodal networks, suffered a loss of their personal substance. As medical anthropologists have argued, in biomedicine, personhood is associated with consciousness and cognitive capacity; and the ways we are constituted as social beings are neglected

(Kaufman 2003; Macdonald et al. 2019). Biomedical conceptualisations of personhood are also blind to the ways in which Yolŋu personhood and agency is constituted through social relations.

Yolŋu who were considered to be victims of sorcery appeared to present in similar ways to displaced renal patients in the circumstances described above, becoming uncommunicative and withdrawn. Sorcery victims were said to be *mukmuk* (silenced through external control). Yolŋu renal patients did not attribute their end stage kidney disease to sorcery in discussions with me[11], and usually offered structural and biomedical explanations for their disease status associated with colonisation and the transition away from hunter-gatherer economies and towards Western diets, as will be discussed in Chapter Eight. However, I suggest that through both sorcery and end stage kidney disease, a nexus exists between intertwined physical illness as social discord or social suffering; the withdrawn presentation of the afflicted; and disempowerment. Through both sorcery and displacement, the quality of one's social relations impacted on one's personal agency and capacity. Healthcare in the context of displacement was problematised by Yolŋu as care provided through an absence of relationality. Through relational personhood, dependency on unknown health professionals and foreign dialysis machines was rendered problematic, not as a lack of independence, but through a lack of relationality.

The requirements of dialysis did not appear to incapacitate patients receiving treatment in their home communities in the same way as those receiving treatment in Darwin. As will be discussed further in Chapter Seven, patients who returned to Galiwin'ku for a brief trial of dialysis in the community appeared to be much more animated and active than when in Darwin, walking to their homelands, hunting and gathering, and taking part in ceremonies. Both patients and health professionals recounted dramatic improvements in returning patients' health, which interlocutors attributed to positive *märr*, being present on country, feeling the presence of ancestors and the dense sociality present in communities. Yinin described patients' lack of agency as produced by the conditions of life in Darwin and as creating dependency. She observed of patients that 'when they are back at home, they are the ones feeding the family. But when they are here (Darwin), they expect the family to feed them'. For Yolŋu, the incommunicability of illness, in a purely linguistic sense, arises from the adverse social relations of illness. Social dimensions of end stage kidney disease and a relational form of agency could have substantial implications for the care that patients required.

[11] Interlocutors sometimes attributed other illnesses to sorcery attacks in conversations with me or in my presence, however. For example, interlocutors attributed a young woman's cancer, a middle-aged woman's stroke, a young man's suicide and a car accident to sorcery. Sorcery victims who I encountered generally sought biomedical treatment.

Conclusions

Yolŋu conceptualisations of health encompass not only physical vitality, but also how Yolŋu are constituted as social beings through relations to kin and country. Through *märr*, personal vitality and agency can be understood as nourished by one's presence on country and maintenance of positive social relations; and apprehended through feelings, thoughts, bodily sensations, impulses and sensory perceptions. End stage kidney disease is experienced by Yolŋu as a social and embodied form of suffering. End stage kidney disease may intertwine bodily pain and discomfort, altered social relations, an absence of agency and a loss of one's personal substance. End stage kidney disease afflicts not only Yolŋu diagnosed with the illness, but also the kin and country they leave behind; and, as the following chapter will explore, those who continue to care for them in Darwin. Through the relational form of agency that Yolŋu embody, care from unknown health professionals could compound patients' social suffering.

Care for Yolŋu with end stage kidney disease can thus be understood as implicated in the personhood, relationality and agency of Yolŋu renal patients. For Yolŋu, health and care both connect individual and collective bodies. In the next chapter, I further explore this conceptualisation of care. I analyse how care is valued and practiced in Yolŋu domestic moral economies. In Chapters Four to Eight, I go on to consider how Yolŋu care practices articulate with the care of the state, through health and social policy.

Chapter Three
Sensibilities, interdependencies and social value of care in Yolŋu domestic moral economies

Bu̲lanydjan seemed to be the only point of fixity in her three bedroom public housing abode in the Darwin suburbs. She sat in her wheelchair by the louvre windows, barely moving except to bring a cigarette to her lips. Meanwhile, her relatives seemed to be in a constant state of movement, bringing home bags full of groceries, busying themselves in the kitchen, rearranging furniture. One woman sprawled out on a mattress on the floor, seemingly exhausted, only to be instructed by Bu̲lanydjan to go and take down washing from the line before the rain came. Like many of my interlocutors, Bu̲lanydjan had several close relatives caring for her. Two of Bu̲lanydjan's siblings' daughters and one of her daughter's sons living with her formed the core of her domestic help. Other relatives also provided temporary care from time to time. Nurses had suggested to Bu̲lanydjan that she consider moving to a nursing home or accessing the services of a professional carer for which she was eligible, but she refused, responding 'I've got three carers here, my brother's daughter, my elder sister's daughter and my grandson'.

Some Yolŋu renal patients, such as Bu̲lanydjan, acquired several carers, of varying degrees of permanence, who tended to be specific kin relations. While interlocutors had widely varying care needs, renal patients are likely to require some form of domestic care in order to manage dialysis treatment, compromised immunity, complications of frailty, dietary and lifestyle changes and to prevent disease progression (Puszka 2019). Moreover, the social suffering of end stage kidney disease described in the previous chapter, experienced by Yolŋu in embodied and social ways, was described as manifesting in diminished personal agency. Social dimensions of end stage kidney disease are likely to further necessitate Yolŋu practices of keeping company in sickness and health, as described by Kerin Coulehan (1996). The ethnographic record shows that in the recent past, Yolŋu and other Indigenous people in northern Australia made distinctions between serious illnesses and injuries,

which required all kin present to provide care; and minor ailments, which were often borne without treatment or expectations of care (Reid 1983; Sansom 1982). The care of people with chronic diseases is not addressed in these accounts. More recently, Francoise Dussart (2010) and Eirik Saethre (2013), both through their work with Warlpiri, argue that the emergence of epidemics of chronic disease may transform expectations and practices of care. In this chapter I show that in the families of some Yolŋu renal patients, end stage kidney disease invokes considerable care.

Approaching relations of care and the agency of carers and patients

This chapter explores how the care of Yolŋu renal patients, as unwell and often elderly people, is practiced and valued in Yolŋu domestic moral economies in order to describe a Yolŋu ethics of care. I argue that relations of domestic care in Yolŋu families are integral to the realisation of social value in people, relationships and family solidarity. Domestic care for renal patients is constituted through relations of interdependency, practices of generalised reciprocity and social roles associated with age, gender and kinship. Domestic care, however, also invokes considerable agentive action, as a performance of kinship and social responsibility. Domestic care in the context of social suffering and displacement, in particular, is likely to require a negotiation of kin relations. In order to address these themes, I bring together scholarship on relations of care and on non-liberal forms of agency, two fields not often connected.

Influential scholars of relations of care in contexts of illness have conceptualised care as a gift of labour not subject to a logic of individual self-interest (Kleinman 2012; Mol 2008). Many subsequent scholars of relations of care have considered how gifts and reciprocities of care are negotiated in families; and how care may at once work to sustain social ties and forms of inequality and indebtedness (Alber & Drotbohm 2015; Baldassar & Merla 2014; Heinemann 2015; Thelen 2015). Other scholars of care have approached caregiving as a relational practice that may not necessarily be purely altruistic, and may be implicated in processes of producing relational forms of personhood or dividual selves, in which the person one is and one's place in the world are defined in relation to others (Chattoo & Ahmad 2008; Hoppe 2020; Kaufman & Morgan 2005). In this chapter I draw on these bodies of work to approach care as a morally ambiguous relation of reciprocity. I extend the scholarship of care in Australian Indigenous societies to consider how the reciprocities of care for people with chronic conditions are constituted; and to analyse how agency is exercised by patients and their caregivers.

In this chapter, I also continue to draw on the anthropology of agency. Scholars of agency in non-Western and non-liberal traditions have argued that approaches to agency that reduce it to resistance to social norms and structures obscure non-liberal forms of agency and self-realization (Asad 2000; Ferguson, J 2013; Mahmood 2001). The reduction of agency to resistance and individual empowerment is also likely to prove inadequate to the task of understanding complex, morally ambiguous relations of care. In this chapter I continue to develop the relational form of agency that Yolŋu inhabit described in the previous chapter and describe how it is invoked through care-giving practices.

Following a brief note on Yolŋu households, I describe the social meanings, organisation and practices of care in the families of Yolŋu renal patients in Darwin. I then go on to analyse how care is constituted in Yolŋu domestic moral economies through material and non-material interdependencies and practices of generalised reciprocity in the pursuit of social value. I consider how Yolŋu have attempted to sustain relations of care and interdependencies of kinship following displacement. I also briefly discuss the ways in which care may be enacted beyond domestic moral economies, involving more distant relatives and different forms of reciprocity, to realise different forms of value. I conclude by discussing how care might be considered a form of social action, and how the displacement of renal patients may in some circumstances reinforce agentively-constituted interdependencies of kinship.

Yolŋu households and domestic moral economy

In north east Arnhem Land, Yolŋu reside in large, multi-generational social housing households[12] of actual and classificatory kin. Household size is likely to be shaped by non-nuclear family structures, as well as public housing design, governed by distant housing bureaucracies (Christie et al. 2013; Fantin 2003). Although practices of polygyny and marriage bestowal have declined in recent times, practices of marrying kin of a particular category continue (Morphy, F 2007b, 2010; Morphy, H 2016; Williams, N 1986). Some households may comprise sets of actual or classificatory sisters married to sets of actual or classificatory brothers and other members of their extended kin networks; or other relatives united by a single ancestor. Families are not bounded by households and extensive mobility exists between dwellings (Morphy, F 2007a). Domestic economies may not necessarily map onto households (Morphy, F 2007b).

[12] Social housing is often the only form of housing available in remote Indigenous communities (see Chapter Five).

In Darwin, Yolŋu renal patients and their kin reside in a range of dwellings. Many reside in social housing located in major complexes, in town camps and dispersed throughout suburban areas; and in hostels offering accommodation to Indigenous visitors to Darwin. Those who are rough sleepers often camp in parks and reserves and on beaches. A small number live in private rental accommodation. Yolŋu communities across Greater Darwin are spatially dispersed and transient, and are concentrated around more stable long-term residents, including renal patients, in social housing and hostels. Many Yolŋu in Darwin continue to reside with extended networks of kin, although practices of co-residence are somewhat curtailed by greater restrictions on numbers of residents and visitors in social housing and hostels (see Chapter Five). Yolŋu domestic economies are more likely to coincide with, or be encompassed within, Yolŋu households in Darwin.

Yolŋu interlocutors made a distinction between care 'inside houses' and care 'outside houses'. Care 'inside houses', in relation to renal patients, comprised tasks such as cooking and cleaning, and particularly intimate forms of labour to support people who were frail and required assistance to perform basic physical functions such as washing, dressing and using the bathroom. Care 'outside houses' could encompass various forms of assistance, including giving lifts in a vehicle and helping people stranded while hunting. My focus in this chapter is primarily on care inside houses, as understood by Yolŋu interlocutors. As will be discussed further in the following section, care indoors invoked particular practices and was understood as appropriately carried out by people in particular forms of kin relationship, however the gendering of care inside houses was somewhat ambiguous.

Social meanings, organisation and practices of domestic care

Domestic care as an affective and embodied performance

Bu<u>l</u>anydjan's daughter's son, Ŋarritj, was one of her main carers. Ŋarritj was in his late 20s and openly identified as a sistergirl (an Indigenous transgender woman). Ŋarritj adopted different gender identities in different contexts and identified as male in conversations with me, referring to himself as 'Bu<u>l</u>anydjan's grandson', and so I refer to Ŋarritj using male pronouns in this thesis.

While Ŋarritj was staying with his mother in Palmerston, a satellite city of Greater Darwin, Bu<u>l</u>anydjan sent his aunt with a request for him to come to Darwin to care for her after another carer departed. Ŋarritj discussed with me how caring for Bu<u>l</u>anydjan quickly became central to his life: 'I went down to (Bu<u>l</u>anydjan's house), I'm staying with her. I've got no one else, that's my home now'. Ŋarritj had

previously worked as a teacher's assistant in north east Arnhem Land. When I first met him, he had recently secured an Indigenous traineeship with a supermarket chain and anticipated starting his new job with some excitement. However, it was evident that he considered looking after his grandmother to be his primary role. He told me that it was his primary reason for residing in the town, commenting, 'when she goes to the next life there will be no point in me coming to Darwin'.

Ŋarritj discussed in detail the kinds of labour that were required to care for Bu̲lanydjan, foregrounding his attentiveness to his grandmother's feelings, thoughts and bodily sensations:

> *I've seen a lot of funerals passed since I've been living with Bu̲lanydjan, the only contact is over the phone, she can only mourn over the phone, she can't go. That's why I think she gets depression, she's beautiful but she's sometimes uptight but I have to stop and think she doesn't do the normal things other Yolŋu do. My job as her carer is to make sure she experiences those normal things, I do it for her….I take her for a walk and she imagines she's walking along with me. I take her all around the beach, all the way from Nightcliff Woolies* (a supermarket chain) *to here along the beach* (approx. 7km)*. Every time she likes to smell the ocean. Even at the beach, it's a small thing but it gets me, I can go to the beach and feel the sand in my feet and walk down and feel the water against my foot, put my foot in the water, but Bu̲lanydjan can't. It's connecting with country and land… Big things doesn't have to be important, just little things makes your life worth living and worthwhile.*

Care, in Ŋarritj's narrative, emerges as an intersubjective relation, requiring embodied insight and empathetic feeling. The attentiveness of Ŋarritj to Bu̲lanydjan's feelings and needs within relations of care constituted through hierarchies of status could also at times be fraught, and he noted that 'sometimes she really needs help and sometimes she's just pulling my leg. She asks to be fed, pushes my buttons'. Ŋarritj, however, was reconciled to the intersubjective nature of his role.

Ŋarritj's knowledge of Bu̲lanydjan's body also required him to perform a mediating role with health professionals. He explained,

> *When the physios come she gets me to tell them which parts of her body have weaknesses, the strength of her grip, only I notice. One of my jobs is to know which part of her body is not functioning. I know her body just as well as she does. I have to step in her shoes and feel her pain and weaknesses in order to fully understand.*

Bu̲lanydjan agreed that of all the carers and health professionals attending to her, her body only responded well to Ŋarritj:

> *…My, my body, doesn't understand checkup, they give me bath, and the other people yes… Only that boy, Ŋarritj. Yes gaminyarr* (son's child - referring to me)*. Yes Karina, my niece, that one, I can feel only like this* (demonstrating difficulty lifting)*, she's really weak from that drinking, yes and her, Jasmine, she's really short and stumpy one. Yes like this, but she want to help me but I said no ...my body its only knows Ŋarritj.*

Several times, on different occasions, Bu̲lanydjan repeated to me the comment that her 'body only knows Ŋarritj', suggesting that his labour represented a way of knowing, feeling and communicating.

Ŋarritj went on to further relate the intersubjective nature of his care for Bu̲lanydjan:

> *Last night my aunt and I cooked rice and coconut cream and magpie goose and barramundi* (a native species of fish) *for her, she finished it all. Every time she eats Balanda ŋatha* (food) *she only eats a little bit, loses her appetite… Once I cooked her - like some food critics say, a taste of the best food brings memories… when I cook her rice she has a different flavour to rice. Yolŋu have songlines about rice. People cook it in a different way, you'll see it at Galiwin'ku, soft and chunky, mixed with tinned beef and spaghetti. She said take me back to Elcho. So I cooked that and made hot black tea, she tasted it and straight away she was sharing stories from Galiwin'ku and what she used to do, confidential stories. She tells me stories, secret stories she doesn't tell anyone else, that means I've earned her trust as one of her carers.*
>
> *…When I hear her say 'I'm living to 100, until I'm 90', that gives me hope and makes me feel happy she's not thinking about dialysis or her disability, she's thinking what normal people think. Because maybe we carers make her feel at home.*

According to Ŋarritj, enabling Bu̲lanydjan to feel like a 'normal woman' required providing care that was felt and embodied. The physical and social displacement of renal patients, which compromised the relational form of agency that Yolŋu embody (discussed in the previous chapter), required substantial forms of care which were physical, affective and intersubjective. Moreover, a shared essence and intersubjective feeling between close kin enabled the communicability of suffering through the bodily feelings and sensations of patients and carers, and enabled carers to apprehend and respond to the social suffering of patients.

Ŋarritj illustrates that the communicability of renal patients' suffering also elicited caregiving as a performance, not only of physical labour, but also of feelings and emotions. I draw here on Basil Sansom's conceptualisation of the performativity of kinship, as relations that are made and reproduced through social action and subject to social recognition and approval (Sansom 1988), without questioning the sincerity or authenticity of Ŋarritj's performance. According to Fiona Magowan (2018: 146), the Yolŋu term *djäl*, translatable as 'want' or 'like', refers to personal needs and desires, as well as proper feelings regarding other people, customary law and a Christian God. Yolŋu associate the term *djäl*, according to Magowan, with proper ways of exercising responsibility. I argue that for Yolŋu, cultivating proper feelings forms part of a repertoire for managing care relations and exercising responsibilities to others.

'Respect' and 'shame': social meanings of care

Bu̲lanydjan was reliant on Ŋarritj's assistance to undertake the basic physical functions of bathing, changing, eating and using the bathroom. Both Bu̲lanydjan and Ŋarritj volunteered candid details of the intimate form of labour that this entailed on several occasions to me, without any prompting on my behalf, speaking of toilet doors left open and the washing of intimate parts of Bu̲lanydjan's body. Bu̲lanydjan did not appear to feel embarrassed or depersonalised by being assisted to carry out such tasks. For example, she explained to me what getting changed in a wheelchair involves in considerable detail:

> *… just try to, this is how I press, put my two feet together, then standing up yes like this. Slowly when I'm on the bed, on the wheelchair of course. And your boy cousin*[13] *comes behind me, my grandson, I hold my hips, just to lift me and pulls me to him. Then I press myself in a lot just to standing up, making myself straight, right? Then all the other object like this,* everything (demonstrating gripping the wheelchair)*, I stand really straight, he help me take my dress and pants off then like this.*

Bu̲lanydjan's detailed narratives suggested much pride in being cared for, further demonstrating affective and intersubjective dimensions of Yolŋu practices of care.

Ŋarritj described assisting Bu̲lanydjan to shower as showing his 'respect' for her, also noting that his care was productive of Bu̲lanydjan's acceptance of his gender identity:

> *When you sit down with Yolŋu then they'll open up their minds and their hearts. Then they'll accept you, welcome you into their comfort zone. Like Bu̲lanydjan, when I first met* (came to care for) *her she didn't really feel confident with me, understand me. But over the last* (next) *few days, the biggest step when I gained her respect and trust was when I gave her a shower. She could see I was there for her, I respected her. Then she was very confident.*

Both Bu̲lanydjan and Ŋarritj appeared intent on impressing on me that their intimate relations of care were productive of respect.

Concepts of 'respect' and 'shame' are fundamental to the Yolŋu vernacular of care. Providing care was often described as expressing one's 'respect', particularly for elders. 'Respect', in some circumstances, could refer to appropriate conduct in relation to or in the presence of anyone older than oneself. For example, an elderly man reprimanded a young girl, who I related to as *yapa* (sister) through fictive kin relations, for her misbehaviour directed towards pets and other children. The older man admonished the young girl to 'stop disrespecting your sister', referring to me. While 'respect' could be enacted in care given to anyone considered to be one's senior, respect for elders took on a particular meaning as

[13] Bu̲lanydjan was referring to my fictive kin relationship with Ŋarritj in this passage.

a relation of deference. When Helen motioned to one of her son's daughters to bring her some porridge from the kitchen and the teenager at first looked away, ignoring her request, another older relative complained, 'those girls have got no respect'. Expressions of 'respect' invoked care as a relation that expressed value in people, and as a relation between generations.

Yolŋu representations of care as expressing respect meant that renal patients' loss of personal capacity was not necessarily a source of embarrassment. Like Ŋarritj and Bu̲lanydjan, other interlocutors also provided accounts of care-giving and care-receiving with some pride. The first time I met one elderly renal patient, along with his daughter's daughter, the young woman volunteered a description of her domestic labour, describing assisting her grandfather to shower, in his presence and without evident embarrassment. She emphasised to me that she was the only family member 'properly caring for him'. Care understood as an expression of respect shaped a patient subjectivity in which bodily dependency was not redolent with stigma.

While care within families expressed respect and social value, interlocutors, including patients of various ages, described being without care as a source of 'shame'. While a lack of care for renal patients could incapacitate them in bodily and social ways, the 'shame' of being without care referred to an absence of respect. Annie described a lack of care from relatives that required her to attend her treatment alone as making her feel 'shame'. Throughout my fieldwork I heard constant rumours about renal patients who interlocutors said were 'not properly looked after' by their families, with the insinuation that those patients were being disrespected, although most of the renal patients I met seemed to be receiving some form of care from relatives. Some renal patients who lacked carers, however, impressed on me the reasons that specific kin were unable to care for them, perhaps not wishing to participate in their own social devaluation. When I asked Wapiriny, another renal patient, about what happened to patients without care, he replied that those patients had 'already gone' – ending their treatment and leaving Darwin to return to their homelands, and gone from this world to another domain. Yinin similarly described patients lacking carers as being especially depleted of *märr,* leading them to take up drinking and cease treatment. The loss of personhood of being disrespected through a lack of care could, for some, make one's life no longer worth living.

As discussed in the previous chapter, the concept of 'shame' in Aboriginal English is typically described in the ethnographic literature as expressing embarrassment or anxiety that results from transgressions of social norms and social isolation (Harkins 1996). Shame therefore may not necessarily result from personal wrongdoing, and may not simply reflect shyness. Natalie Kwok (2005, 2012) has extended anthropological understandings of shame by examining Koori experiences of shame in interactions

with non-Indigenous people. She describes how Koories experience shame as a feeling of unease and inadequacy in non-Indigenous spaces, arguing that shame functions both as a form of internalised racism and a mechanism for Koori autonomy. My Yolŋu interlocutors illustrate that shame in Yolŋu spaces can be counter-posed to care and respect, revealing shame to be an embodiment of a loss of personhood and social devaluation.

Through the terms of 'respect' and 'shame', domestic care emerges as integral to the achievement of personhood through relatedness (Peterson & Taylor 2003). In Yolŋu families, caregiving invests kin and their relationships with value and agency. Through care, Yolŋu experience not only the intersubjectivity of illnesss, but also the affirmation of personhood and kinship.

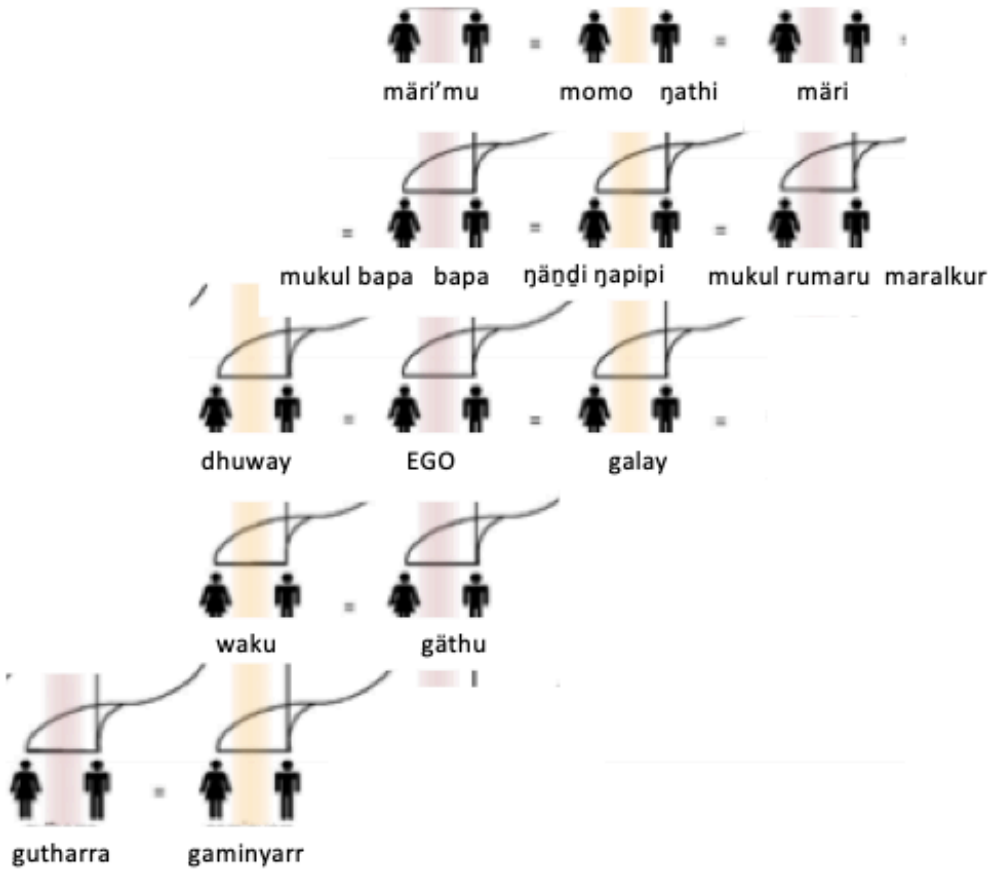
The social organisation of care through generational and gendered relations

Ŋarritj explained that the intimacy and propriety of his relationship with Bu̲lanydjan were sanctioned through their *märi – gutharra* relation (between a mother's mother or mother's mother's brother; and daughter's child or sister's daughter's child; Figure 5):

> *I'm mainly there for Bu̲lanydjan because in the Yolŋu way only grandsons and granddaughters, gutharra can give a shower. When gutharra does that, I'm allowed to touch her private parts. That's my job. She won't feel uncomfortable, awkward. All my brothers and all my sisters (in a Balanda way you might say cousins) can help with the shower, but her favourite is Ŋarritj.*

Bu̲lanydjan herself said that she didn't want men or married couples in her house because she was sometimes wheeled from the bathroom naked, adding that Ŋarritj, her *gutharra,* was an acceptable carer because he was only 27, 'only him'; and some others agreed that gender differences between care-givers and care-receivers were acceptable in the presence of a large age difference.

Figure 5 Yolŋu kinship chart section



Credit: Christie and Gaykamaŋu (2004)

Care, understood as a relationship between generations, was especially implicated by interlocutors in expectations of *märi – gutharra* relations, although not exclusively so. Various interlocutors described *märi – gutharra* relationships as permitting informality and intimacy, and as relationships in which joking and playfulness was expected within age-based hierarchies. Donald Thomson (1949) similarly described Yolŋu *märi – gutharra* relationships as permitting closeness and taunts that might not be tolerated in other circumstances. While intimate relations of care were not possible between people considered to be in 'avoidance' relations such as sons-in-law and mothers-in-law and brothers and sisters[14], several interlocutors also told me that siblings of the same gender should also not provide intimate care for one another, further reflecting care as a relationship between generations[15]. While

[14] In 'avoidance relations', Yolŋu practice social norms of maintaining a respectful distance, such as avoiding eye contact, refraining from directly facing one another or sitting next to one another without another person between, and in some cases, avoiding direct communication or being in each other's presence (Fantin 2003).

[15] Critically ill and dying people were often not visited by siblings, including siblings of the same gender. The bodies of dying people appeared to be considered dangerous, and Yinin suggested that the bodies of siblings of the same gender of a dying person were considered to be in a similarly dangerous state. Siblings tended to wait for news of their relatives' condition in hospital waiting rooms and elsewhere while other relatives, especially

marriage partners also provided care for one another, domestic care for renal patients was not described as primarily constituted through conjugal relations by interlocutors. *Märi – gutharra* relations exist in Yolŋu society as kin relations, but also as a relation between clans. Among clans, *märi – gutharra* relations are constituted through interlocking rights and responsibilities in relation to country and its resources. In the recent past, *märi – gutharra* relations between clans were also structured through the former marriage bestowal system, in which men received wives from their *märi* clan (Keen 2004; Williams, N 1986). Although Yolŋu society is usually described as patrilineal by anthropologists, matrilineal and patrilineal interests both figure, differentially, in the definition of rights and responsibilities associated with land and people (Keen 1995; Morphy, F 2010; Williams, N 1986)[16]. Interlocutors agreed that matrilineages figured prominently in the organisation of care.

The gendering of intimate forms of care for renal patients inside houses was more evident in the construction of care as a matrilineal relation than through gendered expectations of care-givers and care-receivers. The most intimate forms of care were commonly described as appropriately provided to renal patients by their *waku* (a woman's child or sister's child; a man's sister's child) or *gutharra*. *Waku* carers should be the same gender as those they are caring for, I was told, while some interlocutors thought that *gutharra* carers could be of a different gender to those in their care if there was a large age distinction, although others disagreed. Some explained that similarly gendered expectations applied to *gathu* carers (man's child; woman's brother's child), who should be the same gender as those in their care, and *gaminyarr* carers, whose gender did not matter, however there was also no consensus on the appropriate gendering of *gaminyarr* carers. I encountered two young cis-gender men who were caring for elderly female renal patients through *märi – gutharra* relations and a further young cis-gender man who was a care-giver in a *momo – gaminyarr* relation (between a father's mother and a woman's son's child; Figure 5). A further elderly female renal patient expressed a desire for a male *gutharra* to care for her, but could not afford to pay for him to stay with her at her hostel. Different age and gender distinctions may, however, apply to younger Yolŋu requiring care. Three young to middle aged male renal patients told me that if they returned to their home communities, they would be cared for by a *märi* or a wife. While domestic care appeared to be primarily considered a relationship between generations, and there was no consensus on the

---

those who related to the ill person as waku and gutharra, were described as bearing special responsibilities to visit the ill person and keep vigil.

[16] Yinin explained that during mortuary rituals, the deceased person's *waku* and *gutharra*, especially young, able-bodied men and women, have responsibilities to stay close to the coffin and perform much of the labour of caring for guests – preparing food, sweeping and hosing down the ceremonial ground, constructing shelters to shade guests from the sun. The deceased person's *märipulu* (mother's mother's clan) are responsible for directing proceedings, ensuring balance between clans in the allocation of each clan's performances and determining when the ceremony will end. Multiple interlocutors told me that during funeral ceremonies, 'märi takes over'.

appropriate gendering of care, the above suggests that some interlocutors had greater expectations of the caring obligations of younger women compared to those of younger men.

As discussed in the Introduction, the anthropology of Indigenous Australian societies and economies shows that care work in Indigenous societies may not be exclusively constituted through women's social roles (see for example Macdonald 2000; McCoy 2008; Myers 1986). However, household labour in north Australian Indigenous societies has often been described as highly feminised (see for example Burbank 1988; Finlayson 1989; Hamilton 1981; Merlan 1991). The presence of young men as well as women in care-giving roles among my interlocutors, including Ŋarritj, who identified as a sistergirl, and other young men who adopted cis-gender identities, challenges this work on household labour, but reflects the broader literature on care work beyond houses. A lack of consensus among my interlocutors may also indicate that the gendering of household labour has been subject to change since the above-cited work on household labour was undertaken, in the 1980s and 1990s.

The role of Ŋarritj in Bu̲lanydjan's household may have been legitimised, in part, through Ŋarritj's ambiguous gender identity. While Ŋarritj and Bu̲lanydjan had emphasised their *märi – gutharra* relation, a relative insisted that it was their relations of gender, rather than kinship, that made intimate relations of care possible. Referring to Ŋarritj, the woman explained to me that 'he or she was doing that important role as a woman'. Ŋarritj and Bu̲lanydjan did seem to share a close bond that extended to the sharing of sexually explicit jokes, and partaking in the feminised pleasure of dressing up, as Ŋarritj recounted[17]:

> *Every time she goes to renal I put matching clothes on her. On Thursday she was wearing a yellow blanket, yellow top, yellow skirt, yellow shoes18 and I braided her hair and put some perfume on her, her skin was shining. Everyone at renal said your grandson is modelling you, you look really flash. She loves attention.*

Bu̲lanydjan herself appeared to understand Ŋarritj's gender identity in an ambiguous way. Although she referred to him as her 'grandson', she was also known to comment that he was 'a woman trapped in a man's body'. Notably, in Yolŋu matha, pronouns and certain kin relations, including the märi – gutharra relation, are not gendered. This is not the case in all kin relations, however, and there appeared to be less capacity for sistergirls to adopt an ambiguous gender identity in their relations with other kin. Another Yolŋu sistergirl, for example, explained to me that through our fictive kin relation, I would ordinarily have referred to her as ŋapipi (mother's brother), but her sistergirl identity

[17] The sexualisation of care in Bu̲lanydjan and Ŋarritj's relationship was notable, but was not a characteristic of caregiving relations that I observed in other Yolŋu families.
[18] Yellow was a significant colour for Bu̲lanydjan, symbolising her connectedness with certain clans.

made her my ŋändi (mother or mother's sister). It appeared likely that the intersection of kinship and ambiguous gender identity enabled Bulanydjan to make claims on Ŋarritj's caring labour and enabled Ŋarritj's to receive social approval from others for his care work.

Relations of care emerge through Ŋarritj and Bulanydjan's narratives as structured by obligations and expectations of kinship, generation and perhaps gender; and their relations as kin inhabiting a shared essence enabled Ŋarritj to care for Bulanydjan in intersubjective ways. Yet their relationship was evidently a close bond that was forged over time, and was not pre-ordained. Ŋarritj evidently came to occupy the role of a carer through a particular set of circumstances. Generally, Yolŋu families were likely to take into account pragmatic considerations when determining which members would be care-givers to renal patients, including other caring responsibilities amongst young people to their own young children. Yolŋu relations of domestic care, while invoking obligations and entitlements of kinship, generation and gender, emerge as relations that are made, maintained, fractured or renewed through social action and in specific circumstances; and are not given.

Changing practices of collective care

I asked Ŋarritj whether unwell and older Yolŋu were cared for in a similar way in communities in north east Arnhem Land to those in Darwin. He responded by describing the way care was organised in Bulanydjan's household, among himself and three of his aunts, in contrast to the way that Bulanydjan may have been cared for in north east Arnhem Land:

> *That's what she's missing. In Galiwin'ku if someone is sick, that sick person is not only cared for by their immediate family but by the whole community and extended family. When that happens they don't feel alone, they are part of that circle of family and love. Like Jasmine is a carer, I'm Bulanydjan's grandson, Bethany is her niece, Karina is her niece. We all do parts of looking after her, sharing. My main job is to shower her, take her to the toilet, take her for walks. Jasmine is her carer, her job is to pay the power bills and the rent. Jasmine and Karina keep the house clean inside and out.*

Others agreed that sick and elderly Yolŋu were usually cared for collectively in north east Arnhem Land.

This dispersal of care was a common practice in north east Arnhem Land communities, in which I observed babies being circulated through the arms of multiple relatives. While a birth mother was not always aware of where her baby was or who was caring for her, she could be confident that the infant was in receipt of care. Adults with cognitive impairments seemed to wander about their communities alone, but there was a collective attentiveness to their material and immaterial needs. Discussing

people with disabilities in Galiwin'ku, Yinin agreed, 'everyone cares for them, not just one person'. Census data support the contention that caring labour is more widely dispersed amongst Yolŋu than amongst the general Australian population. In the East Arnhem Land region, 47% of respondents reported caring for children in the past two weeks compared to 28% of respondents across Australia, while 17% of East Arnhem Land respondents provided unpaid assistance to people with disabilities, long term illnesses and to elderly people, compared to 11% of respondents Australia-wide (Australian Bureau of Statistics 2016c). Waymamba described collective practices of care as part of a repertoire of intergenerational relations and as expressive of respect for elders:

> *… everybody's involved also, whether you're male or female, look after old man and woman. Because that's the respect they have. They have respect to help us elderly relations. It's part of our tradition, our culture.*

Collective care practices also provided relief for carers, distributing the burden of care work among multiple kin.

Bu<u>l</u>anydjan's displacement to Darwin evidently required remaking relations of care in new ways in her household. Some renal patients receiving treatment in Darwin, like Bu<u>l</u>anydjan, were cared for by multiple relatives, however interlocutors noted that fewer carers were involved than in the care arrangements that would have taken place in their home communities. Care-giving in Darwin evidently required more of individual carers, and as Ŋarritj suggests, could be managed through certain rationalisations and divisions of labour. In Bu<u>l</u>anydjan's household, Jasmine was the only carer receiving the Carer Payment, a social security benefit paid to carers who performed certain kinds and amounts of labour. This was likely the reason that Ŋarritj referred to only Jasmine as 'Bu<u>l</u>anydjan's carer' in his earlier quoted description of the division of labour in Bu<u>l</u>anydjan's household. Jasmine's receipt of the Carer Payment was likely implicated in her role in the household, of managing finances. The responsibilities allocated to Ŋarritj, meanwhile, may have reflected his relation to Bu<u>l</u>anydjan as a *gutharra*, their particular bond and his physical strength. In some families, care arrangements for renal patients living in Darwin were also managed through rotating practices of care, in which visiting relatives would provide care for several months before returning to north east Arnhem Land, to be replaced by another carer. Relations of care within Yolŋu families in Darwin evidently required particular negotiations of social relations, constituting relations of care in new ways which may have worked to formalise the more extensive labour required of carers.

A Yolŋu ethics of care enacted through relations of interdependency in pursuit of social value

Domestic care invested in social value

Bu̲lanydjan had many needs and made many requests of all of her carers, often directing their labour in certain ways. Ŋarritj noted the particularity and intensity of Bu̲lanydjan's requests, describing her as 'an old fashioned diva'. However, I was not left with a sense from Bu̲lanydjan or Ŋarritj that either of them considered their relationship to be one of unidirectional dependency. Ŋarritj described himself as having much to gain from his relationship with Bu̲lanydjan. He agreed that Bu̲lanydjan was also looking after him materially and through consideration of his needs, telling me, 'She is providing a roof over my head. She's always looking out for me, tells me, grab some clean sheets. She looks after me very well'. Ŋarritj further described the non-material dimensions of Bu̲lanydjan's care for him:

> *…In Yolŋu society the rest of my kind are not accepted, sistergirls. But with Bu̲lanydjan she jokes, refers to female parts, makes me feel happy, accepted… she says I'm a woman trapped in a man's body…It was a big change for her too, to be seen by people like me before we had that relationship, but she is beautiful to me, now she fully understands my lifestyle.*

Ŋarritj was committed to caring for Bu̲lanydjan despite his lack of remuneration for his labour. Unlike his aunt Jasmine, Ŋarritj was not receiving a Carer Payment. In fact, Ŋarritj contributed to household rent, bills and groceries. Bu̲lanydjan said that if one of her carers left, she would report them to Centrelink or call on other relatives to remind carers of their responsibilities. Nevertheless, for Ŋarritj, performing the role of a *gutharra* within a *märi – gutharra* relation, understood by Yolŋu as a series of interlocking rights and responsibilities, was a desirable social role.

Not all carers appeared to embrace care work as Ŋarritj did, and some appeared to inhabit a resigned disposition to the sometimes taxing demands of those in their care. Bu̲lanydjan mentioned to me that when she had asked another grandson to bathe her, to whom she also related as *märi,* he baulked. Bu̲lanydjan insinuated that the young man had disrespected her. It was not uncommon for some carers of renal patients to abandon their roles for periods of time and partake in Darwin's nightlife and the availability of alcohol. Ŋarritj, meanwhile, had a male *märi* who was also a renal patient living in Darwin. The man, who was one of Bu̲lanydjan's brothers, was sleeping rough. Ŋarritj visited his other *märi* at the hospital from time to time but was not caring for him in the same intimate way in which he was caring for Bu̲lanydjan.

The desirability of care work among some carers, such as Ŋarritj, can be understood through the investment of care-giving in collective forms of social value within Yolŋu domestic moral economies. Dianne equated care-giving with the exercise of responsibility and power, describing care for elders as nourishing *märr* and safeguarding the inheritance of knowledge that was invested in elders but belonged to whole families or clans. Recalling the representation of blood as a sacred substance of kin relationality discussed in the previous chapter, Dianne explained, 'if I'm sick, there's people looking after my blood and the body containing it'. A *djuŋgaya* (often translated as 'caretaker' or 'manager') is a man or woman with certain responsibilities towards their mother's clan and its country and ceremonies, who manages affairs and brings people together to make decisions. Of the blood of each clan, and the bodies that hold it, Dianne explained, 'djuŋgaya manages it, gutharra cares for it'. In Dianne's account, care-giving for older or unwell kin represents an act of caring for a social body and the substances that bind it and make it well. The limited number of Yolŋu I met who were described by others or themselves as inhabiting the role of *djuŋgaya* tended to be middle aged, while those who represented the *gutharra* in a *märi – gutharra* care relation were usually older teenagers or young adults. Failure on the behalf of a *djuŋgaya* or *gutharra* to fulfil responsibilities of care had broader, collective ramifications, according to Dianne: 'not respecting rom (laws, rules, norms associated with care) devalues our culture. Old people lose value, märr', she told me. Dianne articulated collective responsibilities of care and decision-making, and equated care-giving with the exercise of power and not simply compliance with obligations. She continued, 'more ganydjarr (power) means more responsibility… Gutharra have to look after my father, I can't be everything for him, take all the roles and responsibility'. When care is constructed as producing social value in which care-receivers and care-givers alike partake, care-giving becomes a socially valued role. While the care that renal patients such as Bu̲lanydjan received enabled them to act on the world in ways meaningful to them, care-giving in Yolŋu families can also be considered a form of agentive action invested in producing social value.

Nevertheless, as an expression of value in people and relationships, Yolŋu relations of care in domestic moral economies were also invested in the reproduction of generational hierarchies. Some feminist analyses hold the gendering of care and non-remunerated household labour to be the universal root of women's insubordination (see for example Beneria 1979; Jackson & Jones 1998). Gendered and particularly generational divisions of household labour in Yolŋu domestic moral economies, however, are subject to different forms of value than those presupposed in such analyses. Gendered and generational divisions of caring labour in Yolŋu households can be understood as contributing to collective forms of social value in which all partake. Marilyn Strathern (1988) has argued forcefully that in households in Hagen, Papua New Guinea, while status hierarchies of gender exist, women's

household labour is not devalued as it contributes to collective forms of value. Women's household labour is invested in the rearing of pigs that produce social value in ceremonial gift exchange undertaken by men in a public domain. Women who rear pigs are not alienated from the products of their labour, according to Strathern, as women also partake in the social status acquired by their husbands through the gifting of the pigs. In Yolŋu domestic moral economies, caring labour invested in respect, elders' knowledge and *märr* does not denigrate carers and is not rendered invisible. Notably, Indigenous feminists such as Aileen Moreton-Robinson (2000) have tended to articulate pro-natalist aspirations which celebrate the social roles of Indigenous women as carers and which seek to change the position of Indigenous women in broader society but not necessarily in Indigenous societies. The caring labour of young Yolŋu men and women, while reproductive of generational hierarchies, is invested in socially recognised forms of worth. Young Yolŋu carers, like Hagen women, are not alienated from the collective forms of value to which they contribute.

Care work in Yolŋu domestic moral economies can further be understood as conferring social value on care-givers in comparison to their peers. Carers who abandoned their roles or who were seen to be 'not properly looking after' those in their care were likely to be met with scorn within and beyond their families, and accusations of disrespectful behaviour and immaturity. For carers who abandoned the sometimes taxing work of domestic care and partook in other forms of sociality such as drinking binges, the value of personal autonomy could conflict with the maintenance of relatedness, as Fred Myers (1986) has argued. Dianne expressed care-giving as the exercising of power and responsibility within the confines of age-based social roles; and carers were likely to earn broad social approval. Other interlocutors, for example, noted that 'only Ŋarritj' appeared to be capable of fulfilling many of Bu̲lanydjan's needs and that he was performing an 'important role'. The desirability of care work among some younger Yolŋu carers can be understood through the capacity for carers to gain recognition as people who respond to others' needs, within generational hierarchies. As Gaynor Macdonald (2000) has argued in relation to Wiradjuri forms of relational personhood, one's desire to be recognised as a particular kind of kinsperson requires one to recognise and respond to the care needs of others in turn. Ŋarritj notes that his gender identity and needs are recognised by Bu̲lanydjan as a result of his care-giving role. Paradoxically, by personifying a normative role of a female *gutharra* and producing socially recognised forms of value, Ŋarritj's sistergirl identity was accepted and his kinship relations affirmed. Ŋarritj embodies what George Paul Meiu (2015) describes as a 'queer moment', or a subversive means of achieving otherwise normative forms of value. While Ŋarritj's sistergirl identity marked his relationship with Bu̲lanydjan as an interdependent relation of mutual recognition in particular ways, interdependent relations of mutual recognition and an ethic of

recognising others' needs were intrinsic to practices of care for renal patients in Yolŋu domestic moral economies.

Ŋarritj described gaining privileged access to Bu̲la̲nydjan's knowledge as a result of their relations of care. Notably, eldership in Yolŋu society is not only a status of age but also a status associated with knowledge and authority, applying to older Yolŋu who have acquired particular knowledge over their lifecourses and whose parents are no longer alive. One Yolŋu woman in her late 40s could acquire the status of an elder through her knowledge and ability to exercise authority, where another in her early 40s who occasionally went on drinking binges and was thought by others to lack responsibility could be described as a 'young person'. Performing domestic care evidently takes on different meanings in Yolŋu domestic moral economies to the meanings of domestic care in Western societies in which social status is closely tied to one's career in the formal economy. In Yolŋu domestic moral economies, care-giving could form part of one's life trajectory in Yolŋu society.

Dianne's evocation of care work as responsibility and power exercised within gendered and particularly age-based social roles foregrounds agentive dimensions of social obligation. As Jane Guyer has argued of Western societies, through 'responsibility', obligation registers an active voice in which the following of rules and norms is complemented by acting on one's sensibility of one's responsibilities (Guyer 2012). Elizabeth Povinelli (2002) has meanwhile contrasted late liberal understandings of obligation as a social force with Indigenous conceptualisations of obligation as a moral sensibility that mobilises intuition and embodied insight. In Ŋarritj's account, subjecting oneself to gendered and particularly generational social obligations of care involved considerable agency, through the mobilisation of embodied, sensory and affective labour.

Domestic care enacted through relations of reciprocity and interdependency

In Yolŋu domestic moral economies, social value is produced through caring relations of interdependency and practices of reciprocity. As scholars of disability studies and social gerontology note, even relations of care of people with substantial care needs are unlikely to be entirely one-sided or devoid of reciprocity (Baldock 1997; Fine, M & Glendinning 2005; Rummery & Fine 2012). However, scholars of reciprocities of care such as Laura Heinemann also point out that care-giving contains 'dual possibilities of mutuality and parasitism, generosity and exploitation' (Heinemann 2015: 38). In this section I discuss how Yolŋu construct legitimate reciprocities of care in the presence of status inequalities between older and younger generations, while acknowledging that reciprocities of care

may not always be fully realised. I discuss how reciprocities of care are enacted by Yolŋu within a proximate temporality and over the lifecourse.

In an immediate timeframe, reciprocities of care for renal patients encompassed material and non-material dimensions of care-giving. While Yolŋu carers were often unremunerated, renal patients in their care generally had a greater capacity than their carers and other kin to mobilise welfare resources, such as social housing and Age Pensions or Disability Support Pensions. While not all carers were employed in the formal economy as Ŋarritj was, some renal patients had acquired what Gaynor Macdonald (2000, 2018) terms 'allocative power', or the capacity to respond to the needs of kin through access to resources and willingness to engage in sharing practices. As Helen noted of her visiting kin, who kept her company and assisted with household chores while she provided them with accommodation and food, 'I look after them and they look after me'. As will be explored further in Chapters Five and Six, the interdependencies of care between renal patients and their kin were patterned by interlocking material and non-material reciprocities. However, care for renal patients was embedded in much broader forms of value and more complex relations of interdependency than those contained in a simple exchange of caring labour for material resources. As Annemarie Mol reminds us, care is a process, not a transaction; and a relation, not a product (Mol 2008).

Care for renal patients was encompassed by wider caring relations of reciprocity and interdependency. Some renal patients, particularly but not exclusively older women, were heavily involved in the care of babies and young children in their families, especially when babies' and children's parents were teenagers or young adults. When one renal patient's granddaughter, who was sleeping rough, gave birth to a baby girl, the elderly woman offered to take responsibility for the child in order to prevent her from being placed in out of home care. After nurses assessed the elderly woman to be a poor choice of guardian due to her health status as a renal patient and her inability to provide care during the hours she spent on dialysis, the family came to an arrangement in which the elderly woman and her non-Indigenous carer would jointly adopt the baby. The arrangement enabled the child to be cared for materially, while also being socialised into her place in a Yolŋu lifeworld. Health professionals had recommended to Wapiriny that he consider moving from the house he shared with his wife, mother in law, daughter and several young and teenaged grandchildren, and into a nursing home. Wapiriny declined, explaining to me that he was concerned about relinquishing care for grandchildren living with him.

Through reciprocities of care within Yolŋu domestic moral economies, younger carers were attributed significant responsibility for performing physical forms of labour; while the responsibilities of the

elderly included duties to deploy their moral authority for the collective benefit of their families. As Ŋarritj suggests, the caring responsibilities of older Yolŋu could be expressed as responsibilities to make arrangements for one's carers and ensure that they are not overwhelmed with care work. I was often called on to assist interlocutors and their relatives in their dealings with various social services and with transport around Darwin, as well as in other ways. Some older Yolŋu, however, expressed concern at different times that I wasn't spending enough time with my partner, or that I had other work to do. The responsibilities of elders could extend to the use of their authority and ability to articulate their households' needs in interactions with the staff of social services for the benefit of their carers. Helen and her middle-aged daughter and carer, Bilinydjan, resided together at Helen's public housing unit. They had been seeking a larger house from housing department staff, with more space for Bilinydjan's partner and children as well as visitors, as will be further explored in Chapter Five. Throughout their prolonged dealings with departmental staff, Helen had done much of the talking. Yinin commented on the literal and metaphorical reciprocities of care between Helen and Bilinydjan. Referencing Bilinydjan's social status as a young person, Yinin remarked, 'Can you imagine Bilinydjan without Helen? Helen is her warraw, her shelter. Bilinydjan is too shy to talk to others by herself, she's young'. Young carers were reliant on older renal patients in their care to advocate for their needs as carers, within their families as well as to the state.

As in Bourdieu's contribution to gift theory, alternative temporal framings of care result in different constructions of the reciprocities of care-giving (Bourdieu 1977). While the reciprocities of care in Yolŋu families were more evident in a proximate temporality, interlocutors also agreed that the nurturance of younger generations by older kin provided a basis of the obligations of the young to care for their elders. Care for renal patients can be represented as a reciprocal exchange of care over lifecourses, in which renal patients' care figures as the repayment of a debt owed by a younger to an older generation. As Annette Weiner argued more generally, care for renal patients, when perceived from a broader vantage point of reciprocities and interdependencies over the lifecourse, could be valued as a practice of social reproduction (Weiner 1980).

Within Yolŋu families, renal patients are cared for through networks of generalised reciprocity, a weak form of reciprocity in which there is no accounting of social debts in terms of number or magnitude (Sahlins 1974: 193-194). Younger Yolŋu care for older generations as an open-ended form of contribution that encompasses both abiding and immediate obligations and entitlements. Several scholars of Australian Indigenous societies characterise the care provided to children as providing the basis for children's subsequent obligations over their lifecourse to all kin who nurtured them. Children's nurturance also provides the basis upon which nurturers accept responsibility to provide

children with food, shelter, protection and knowledge throughout life (Finlayson 1989; McCoy 2008; Myers 1986; von Sturmer 1980). Diane von Sturmer describes obligations amongst Kugu-Nganychara adults to 'work for' kin who nurtured them as children, and to care for their elderly nurturers (von Sturmer 1980: 15). Fred Myers argued that Pintupi boys who are transformed into men through initiation and nurturance by senior men acquire social obligations and debts to their nurturers that can never be fully repaid (Myers 1986). Similarly, the care provided by younger Yolŋu to kin with kidney disease is encapsulated within a broader frameworks of rights and obligations of care, and does not erase inequalities of status between the old and young which may be constituted through the earlier nurturance of the young by older generations. However, in contrast to some of the works cited above, I have foregrounded agentive dimensions of subjecting oneself to social obligations of caregiving. Care is enacted in Yolŋu families through generalised reciprocity, a weak form of reciprocity, in which obligations and entitlements to care may exist in potentiality and social debts may not always be repaid. The care of renal patients is enacted through the performance of kinship and social roles by both care-givers and the recipients of care.

The care-giving practices in Yolŋu families that I have described demonstrate that the reciprocities of care invoke a relational form of agency. As Saba Mahmood (2001: 210) has argued in a manuscript on Muslim women's practices of piety, agency encompasses how 'individuals work on themselves to be the willing subjects' of a particular set of values and practices. In Yolŋu families, the care of renal patients could at times be taxing and was propelled if not compelled through age-based and gendered social roles and norms. Despite this, Yolŋu families' expectations of care-giving by younger kin were not always fulfilled, and young Yolŋu who took up care-giving roles exercised a measure of autonomy. Moreover, collective practices of care-giving, which distributed labour among multiple carers, provided some scope for autonomy within relations of care. Among carers, agency was invoked in the performance of responsibility and the pursuit of individual and collective social value, enabling carers to gain recognition within their families and communities in comparison to their peers. For Ŋarritj, subjection to social norms and roles associated with age and gender through care-giving led to the transformation of his relatives' attitudes regarding his gender identity. For younger Yolŋu, taking up the role of a carer could also represent a strategic move in the pursuit of material subsistence, in the context of the structural inequalities and poverty that many contend with. The capacity of carers to act on the world in ways meaningful to them can thus be understood as exercised through normative practices of care.

In relations of care in Yolŋu families, relational forms of agency may be exercised through networks of interdependency. James Ferguson argues that in Southern Africa, legitimate forms of agency may be

enacted through making oneself materially dependent on others, in pursuit of social membership and basic material needs (Ferguson, J 2013). I somewhat similarly suggest that the physical dependency of renal patients on their care-givers enables them to act in meaningful ways, in pursuit of self-realisation and basic needs. For some Yolŋu renal patients, depending on the care of kin enabled them to perform basic bodily functions and social roles such as managing households and distributing domestic work among family members. The moral authority of older patients as elders required the respect and care of younger relatives. In some cases, I have argued, through relational forms of personhood, carers who recognized renal patients as kin in need could provide renal patients with a life worth living. The physical dependency of patients on their care-givers is constituted through broader familial relations of interdependency, in which care-givers often relied on those in their care for their basic material needs, and on care-giving practices to earn recognition and status. The capacity of both patients and carers to act meaningfully in pursuit of social value and basic needs can thus be understood as emerging from the actions of each other.

A Yolŋu ethics of care is constituted in Yolŋu domestic moral economies through relations of interdependency and generalised reciprocity. Interdependencies and practices of generalised reciprocity of care in Yolŋu domestic moral economies encompass physical labour, material resources and processes of recognition and personhood. Relations of care in Yolŋu families require considerable work in relation to one's own feelings and desires and in the negotiation of one's relations with others. In this chapter, I have brought together two strands of care scholarship and scholarship on non-liberal forms of agency to consider how both personhood and relatedness to others are constituted through the care of Yolŋu renal patients. Among Yolŋu, relational forms of personhood and social and material interdependencies can give rise to ways of acting within relations of care that do not construct a binary between altruism and self-interest. The forms of agency that Yolŋu exercise in giving and receiving care call into question the characterisation of care-giving by some scholars as a practice caught between the poles of altruism and the exercise of power over others (Rapport 2018; Thelen 2015). As the following section will explore, the reconstitution of domestic care in a context of displacement to Darwin could lead families to negotiate a Yolŋu ethics and practice of care in different ways.

Refiguring the interdependencies of care

The displacement and sedentarisation of renal patients in Darwin could reconfigure relations of care within families. In contrast to the broad dispersal of caring labour within families in north east Arnhem

Land communities, care tended to be concentrated among a smaller number of relatives in Darwin, while the physical and social dimensions of end stage kidney disease, including the withdrawn, incommunicative presentation of some patients and the inhibited power and agency that were attributed to deficient *märr,* discussed in the previous chapter, could also create many demands on carers. For some carers, the displacement of renal patients to Darwin could occasion conflicting responsibilities to care for renal patients and other relatives in north east Arnhem Land. Patients themselves also described displacement from their own responsibilities of care in their communities (see Chapter Seven). Some claimed that the power of elders and their ability to influence compliance with social norms of care was diminished in Darwin, while the allure of alcohol and Darwin's nightlife could intensify the tensions between autonomy and relatedness in relations of care.

As previous sections have discussed, families attempted to sustain relations of care and the production of value in people and relationships in Darwin through the adaptation of care practices. Renal patients residing in Darwin were likely to be cared for by fewer carers in contrast to domestic care arrangements in north east Arnhem Land. While carers in Darwin were likely to sustain higher workloads, their labour could be somewhat ameliorated through the rotation of carers. Such arrangements could work to formalise care relations, through divisions of caring labour and a clearer articulation of those responsible for performing specific tasks. Yinin explained to me that in Darwin, carers were more likely to seek remuneration through the Carer Payment, and this may have represented a response to the increased demands on carers' labour and the greater formalisation of care work; and perhaps also the increased living expenses sustained by Darwin residents (see Chapter Six).

There were other ways in which Yolŋu attempted to enact the care of renal patients as a formalised relation, beyond domestic moral economies. While some such as Bu<u>l</u>anydjan expressed an aversion to unknown hired help available through the care of the state, in exceptional cases, relations of care could encompass distant people and places in response to the centralisation of renal services. *Bala-räli* was a term that interlocutors used from time to time, literally meaning 'towards and away', or 'two directions', which was often used to describe material and immaterial forms of balanced exchange between people or groups. In a discussion about how care was operationalized, Wapiriny told me, 'through family we help each other, bala-rälimirr (through exchange)'. Yinin explained that if someone was caring for Bu<u>l</u>anydjan in Darwin, hypothetically, and they were not a member of her close family group, a member of Bu<u>l</u>anydjan's family group in Galiwin'ku might help the carer's family, through an exchange of labour. For instance, if the carer's relatives became stranded while hunting, Bu<u>l</u>anydjan's

family would be compelled to render assistance. *Bala-räli* provides a means of achieving balance in social transactions in a more proximate timeframe and was invoked in relations with outsiders.

Relations of care comprising people from different family groups attracted a different moral and economic evaluation to the reciprocities of familial care. Care within families did not carry expectations of direct reciprocation or create social debt. Care relations constituted between family groups or more distant kin, however, could be subject to expectations of balanced exchange. Care for more distant relatives implied neglecting one's own family, and was understood to produce social debts between family groups. Labour not directed towards internal group solidarity and value but towards external connections in Yolŋu nodal networks appeared to attract compensation. *Bala-räli* care relations between families recalled the political relations between Yolŋu families and clans, which are usually represented as relations of formal equality and balance (see for example Magowan 2018; Thomson 1949; Yolŋu Nations Aboriginal Corporation 2018; see also Chapter Eight). Care in this sense, encompassing labour inside and outside of houses, is seemingly still not fully commensurable with other forms of value, and can only be exchanged for more care. Here, debts of care produce a different kind of interdependency and social value, helping to sustain relationality between groups.

An instance of *bala-räli* care practices between family groups arose when Helen's daughter Bilinydjan and her children returned to north east Arnhem Land for one or two months to visit another elderly relative. Helen told me repeatedly that Bilinydjan was her ideal carer and the person whom she felt most comfortable being cared for by: 'I can talk to Bilinydjan, she's my right daughter, more easier. Other carers, sometimes I can't talk to them'. While Bilinydjan was away, Helen's son and daughter-in-law came to take their place. On occasions when I visited Helen while we sat on her living room floor talking, the couple busied themselves sweeping the floor, washing dishes, buying groceries and withdrawing money for Helen from her bank card at her request. However, I was told that the true commitments of Helen's daughter-in-law were to her own kin. Helen, therefore, owed the woman a special debt. Helen's discomfort with her temporary carers contrasted with the deep relationship she maintained with her daughter which was inscribed with several years of domestic care. Nevertheless, Helen seemed to be able to communicate her needs to the couple, and they seemed to oblige. Helen's discomfort may be understood as a product of the debts understood to accrue to her daughter-in-law. *Bala-räli* care practices, however, did not appear to be widespread amongst interlocutors, and so the concept as developed here carries some contingency. Almost all other interlocutors with whom I discussed care negotiated through *bala-räli* reciprocities seemed uncomfortable with the prospect, commenting that intimate care should properly take place between close relatives.

Bala-räli relations of care, as a form of balanced exchange between families, could continue to invoke interdependencies and practices of genealised reciprocity within family groups. Social debts accrued through *bala-räli* relations of care could be understood as collective forms of liability. Yinin explained to me that her sister, a renal patient who required a wheelchair, '…lets me know, asks my advice if a person is going to come, a carer to come and look after her – take her to the shops, for a walk, anywhere, in the house, outside. Later on, I'll help them. If I see their family I'll offer them a lift, without them asking'. Care negotiated through processes of *bala-räli* further illustrates how care for renal patients requires a negotiation of social relations, and could invoke reciprocities, both within and between family groups.

Conclusions

In this chapter I have described a Yolŋu ethics and practice of care. I have shown that the care for Yolŋu with end stage kidney disease is constituted in domestic moral economies through relations of interdependency and practices of generalised reciprocity amongst kin. Interdependencies of care are enacted through social roles associated with age, gender and kinship and interlocking material and non-material obligations. Interdependent relations among kin may further extend to processes of recognising personhood through relatedness, through the recognition of one's basic needs by others and in responding to those of kin. Interdependencies amongst kin may also invoke welfare resources. The bodily and social dependency of renal patients on their familial carers does not translate to social debts or social inequalities amongst kin as the dependency of renal patients is encompassed within broader relations of interdependency.

As the previous chapter showed, the physical and social dimensions of end stage kidney disease could lead to substantial care needs among Yolŋu renal patients. In this chapter I have considered how Yolŋu exercise agency in relations of care for renal patients, drawing on and contributing to the anthropology of care-giving in Australian Indigenous societies and to international scholarship on care. I have argued that in Yolŋu families, both the giving and receiving of care invokes relational forms of agency, as a performance of kinship and responsibility by both renal patients and carers, and as a strategic practice on the behalf of carers in the pursuit of social recognition and the basic needs of life. Some families went to great lengths to ensure that renal patients displaced to Darwin were cared for, and urban displacement could increase the workloads of carers considerably. Care-giving requires substantial amounts of work, not only through the physical, sensory and affective dimensions of care-giving, but also through the negotiation of social relations and sometimes conflicting values and

desires; and takes place in circumstances that can be both precarious and taxing. The work involved in maintaining relations of care, however, could remain invisible to the state, as following chapters will explore. In the following three chapters I consider the intersection of Yolŋu values and practices of care with healthcare, social housing and social security.

I have described the care of Yolŋu renal patients in Yolŋu domestic moral economies as heavily invested in the production of social value, of a relational self, respect, elders' knowledge, *märr* and intersubjectivity. The production of social value was likely to reproduce age-based social hierarchies. Yet for some carers, conformity with generational social obligations of care could be both desirable and compelling, as a contribution to collective forms of social value in which all partake. Conformity with obligations of care amongst some carers may also reflect the pursuit of relational forms of personhood, social status and material subsistence in the context of the structural conditions that carers inhabited. An epidemic of end stage kidney disease among Yolŋu can thus be understood as reinforcing interdependent relations of care between generations of kin in some circumstances. In Chapter Six, I also explore how the disrupted lifecourses of younger renal patients undertaking dialysis in Darwin could trouble expectations and obligations of care.

Chapter Four Interdependencies and reciprocities of healthcare: Therapeutic relationships in Darwin renal services

Figure 6 Nightcliff Renal Unit

Credit: Stefanie Puszka

The exterior of the Nightcliff Renal Unit facility featured Indigenous artwork juxtaposed with windows overlaid with iron cages (Figure 6). Relations of care inside the building encompassed similarly contending values of care. In this chapter I explore care as a social relation of reciprocity at the Nightcliff Renal Unit and on the renal wards of Royal Darwin Hospital.

Influential scholars of relations of care in healthcare conceptualise care as a gift of labour not subject to a logic of individual self-interest (Kleinman 2012; Mol 2008). Many scholars of relations of care have considered how gifts and reciprocities of care are negotiated, and how care may at once work to sustain social ties and gendered and racial inequalities (Alber & Drotbohm 2015; Baldassar & Merla

2014; Heinemann 2015; Thelen 2015). State-sponsored healthcare has been described as a relation of reciprocity between patients and health professionals or states, through which patients accrue social debts (Andaya 2009; Kyeong Seo 2016). I consider how healthcare was enacted in Darwin renal wards and units through reciprocities between Yolŋu renal patients and health professionals with disparate expectations of where the obligations and limits of care lie.

I argue that Yolŋu attempt to realise social value and a Yolŋu ethics of care through healthcare. Through renal services, Yolŋu attempt to enact care that expresses respect, attentiveness to individual bodies, relations between generations, generalised reciprocity and interdependency. Health professionals, through their care for patients, attempt to cultivate patient empowerment and independence while concurrently mobilising relations of domestic care among kin in the pursuit of health policy agendas. I explore the interaction of disparate values and practices of care through both health professionals' and patients' attempts to make healthcare amenable to their values of care.

Healthcare figures prominently in past and present Australian race relations. Heavily implicated in paternalist dimensions of colonisation, provision of healthcare to Indigenous populations provided part of the rationale for institutionalising Indigenous people in missions and on reserves in the 19th and 20th Centuries (Long, J 1970: 5). Contemporary state-sponsored healthcare for Indigenous Australians struggles to overcome colonial legacies of assimilation and population surveillance and control. Health services and their staff grapple with themes of staff responsibility and patient autonomy, universal access to treatment and cultural alterity (Kowal 2008; Lea 2008; Sanders 2014). Medical anthropologists have often described the practices and imperatives of contemporary biomedicine and its practitioners as conflicting with Indigenous sociality and social practices in various ways (Anderson, I 1995; Dussart 2010; Heil 2006; Heil & Macdonald 2008; McCoy 2008; Saethre 2013; Senior & Chenhall 2013). Attempts to make biomedicine more amenable to Indigenous patients have often deployed, and have often been troubled by, therapeutic relationships between health professionals and patients (Kowal 2015; Lea 2008; Myers 1986; Saethre 2013).

Tess Lea, in her landmark ethnography of the Northern Territory Department of Health (then known as Territory Health Services), describes how health policymakers and health professionals embodying liberal, culturally sensitive subjectivities come to know Indigenous people in heavily constrained, socially authorised ways (Lea 2008). Desires to improve Indigenous health through non-colonising means promote a social distance between Lea's interlocutors and their patients. Paradoxically, past failures to improve Indigenous health sustain further intervention into Indigenous patients' lives

through a remedial logic that legitimates the positions that health policymakers and health professionals occupy and perpetuates the helping subjectivities that they embody.

Emma Kowal's work with interlocutors she describes as 'white anti-racists', who are employed to work on Indigenous health projects in the Northern Territory, also takes up the topic of race relations in healthcare (Kowal 2015). Kowal provocatively asks whether white anti-racists' desires to help are also desires to dominate. Exploring tensions between structure and agency in Indigenous health projects, Kowal argues that in attributing the causes of Indigenous ill-health to structural factors associated with colonisation, white anti-racists credit Indigenous people with little agency. A logic of 'overstructuralism', according to Kowal, causes white anti-racists to problematize their own agency in intervening in Indigenous peoples' lives, and to fear that they are at once doing too much and too little.

As with Lea and Kowal's interlocutors, renal health professionals I interviewed often embodied liberal subjectivities and described their work as infused with moral value. In doing so, they embraced institutionalised norms of sensitivity to cultural alterity. The Department of Health's Aboriginal Cultural Security Framework instructed staff to ensure that 'Aboriginal consumers are provided with care that is responsive to (their) needs and values' (Northern Territory Government 2016). The Framework offered little guidance to staff on how they should approach this task, perhaps necessarily, as culture is not amenable to codification. While my health professional interlocutors were often not white themselves, and many were migrants from a variety of Asian backgrounds, they expressed similar discomfort about patients' dependency on the state and about their own interventions into patients' lives. However, where Kowal and particularly Lea's interlocutors maintained a distance from their clients, the nature of dialysis treatment required my interlocutors to be in close physical proximity to patients, and enabled some patients and staff to develop relationships of familiarity. Through the intimacy of therapeutic relationships in Darwin renal units and wards, questions about the meanings and expectations of care in healthcare arise. While the approaches adopted by Lea and Kowal both emphasise the forms of subjectivity adopted by non-Indigenous professionals, my starting point is the encounters between health professionals and patients and the interaction of divergent ethics and practices of care.

I commence with an exploration of the ways in which Yolŋu renal patients and renal health professionals come to relate to one another. I examine the requests of care made by patients and health professionals' responses to patients' requests. While Yolŋu values of care were discussed in the previous chapter, here I explore the values of care articulated and embodied by health professionals,

analysing themes of empowerment, responsibilisation and paternalism. Self care dialysis and a patient proposal for the employment of Yolŋu in renal services are examined as particular sites through which conflicting values and expectations of care play out. Although I approach patients and health professionals dichotomously in this chapter in order to examine disparate values and expectations associated with the giving and receiving of healthcare, patients and staff were not homogeneous groups; and I also describe some internal distinctions among both.

Healthcare as a relational practice

A social gulf in therapeutic relationships

Few Indigenous health professionals are employed in Northern Territory renal services beyond identified positions such as Indigenous Liaison Officers (Lahn et al. 2020). Identified positions in Darwin renal services were not responsible for the direct administration of dialysis and none were occupied by Yolŋu throughout my fieldwork[19]. In the Northern Territory, dialysis is overwhelmingly administered by renal nurses, who have tertiary qualifications (Gorham et al. 2016). Around 85% of Northern Territory renal service staff are trained overseas (Gorham et al. 2018); and health professionals trained in Australia are highly likely to have relocated to the Northern Territory from other parts of Australia (Garnett et al. 2008). Differences between health professionals and patients of cultural background, socio-economic circumstance and life experience created a social gulf in therapeutic relationships.

The social gulf between health professionals and patients was compounded by language differences and biomedical practices that could cause offence. Biomedical practices involving a barrage of direct questions, a lack of privacy in personal affairs and health professionals providing treatment to patients of a different gender may all offend Indigenous expectations of interpersonal relations (Dussart 2010; Harris 1987; Saethre 2013). The exposure of blood, considered an intimate and dangerous substance by Yolŋu, could also cause distress (Reid 1983). Miscommunication and misunderstanding between renal patients who spoke Yolŋu languages as their first languages and their health professionals have also been documented in Darwin renal services, in addition to problems of gratuitous concurrence (Lowell et al. 2005). For Yolŋu patients, being cared for by strangers, without consideration of relationships, social position or gender, was a disconcerting practice. As discussed in Chapter Two,

[19] Indigenous Liaison Officers in Northern Territory renal services have very high patient loads (Gorham et al. 2016). Staff members occupying Indigenous Liaison Officer roles changed several times throughout my fieldwork and some positions remained vacant for a number of months at times.

Yolŋu described receiving care from unknown health professionals as diminishing patients' power and agency, and as leading some patients to become incommunicative.

Despite the social gulf between Yolŋu renal patients and health professionals, patients articulated desires to establish relationships of care with health professionals, beyond the provision of treatment. One patient, Jeffrey, discussed the need for better doctors, commenting that those working at the renal unit 'only see the numbers, put into the computer, tell you you're sick or manymak (good)'. Waymamba explained, 'dialysis is helping us to clean up our blood in the system but it's not really helping us get well'. On another occasion, in a conversation with Waymamba and Mr Muŋul̲purr about differences between biomedicine and Yolŋu conceptualisations of health and care, Waymamba commented, 'Western culture is to me like whether you want to get treatment or not', suggesting that she experienced biomedicine as devoid of care. Distinctions between treatment and care made by interlocutors did not necessarily represent different kinds of labour, but its capacity to register different kinds of value. During the same conversation, Mr Muŋul̲purr commented, '(the) first thing nurses and doctors say is this medicine cost lotta rrupiya (money), to get this medicine in Darwin. But we don't like that answer, because in our society it's free. The old lady say go and get that thing[20] and put it on your sore'. Although dialysis was provided to patients free of charge in the Northern Territory, health professionals at times reminded patients of the costs that their treatment presented to governments, particularly when patients returned to their communities, missed dialysis and required medical evacuation. Health professionals who reminded patients of the costs of their treatment may have represented to Mr Muŋul̲purr treatment provided without generosity, compassion or respect. For Yolŋu patients, transforming treatment into care and enacting relational forms of agency in healthcare contexts required establishing certain kinds of relationships with health professionals.

Health professionals in Darwin renal wards and units also discussed their desires for reciprocal, collaborative relations with patients in order to counter what they described as the 'disengagement' of patients from their care. Incommunicative patients made health professionals' work acutely difficult, and made for awkward clinical encounters. Incommunicative patients could also raise questions about patients' consent for treatment. As Baldock (1997: 82-82) and Mol (2008) have both argued, the responses of care receivers are intrinsic to the quality and success of the provision of care. Many of the health professionals I spoke to described their pursuit of careers in renal services as motivated by the possibility of regular, ongoing contact with the same patients and the opportunities

[20] Mr Muŋul̲purr referred to a customary treatment to remove infection from boils, through the application of bark soaked in water with the leaves of a specific species of tree.

it presented for long-term relationships. Others who described themselves as falling into career paths in renal services said they had not moved on to other areas of healthcare because working in renal services provided greater opportunities for them to get to know their patients.

Finding ways to relate to one another

Yolŋu patients attempted to find ways to relate to health professionals. Mr Muŋul̲purr agreed that when patients knew doctors and nurses, they would talk openly. In fact, some patients, including Mr Muŋul̲purr, were highly involved in their care.

At the Nightcliff Renal Unit one morning, I observed nurses connecting patients to dialysis machines at the start of their shift. Mr Muŋul̲purr was waiting in his regular dialysis chair with a blanket over his lap when Lena, a renal nurse, came to arrange his vascular access. Lena greeted Mr Muŋul̲purr, 'Good morning märi (mother's mother's brother), how are you today?' Mr Muŋul̲purr replied 'manymak (good)', nodding his head. Lena checked Mr Muŋul̲purr's foot circulation, and then cleaned his fistula[21] with a wipe before inserting a local anaesthetic, causing Mr Muŋul̲purr to wince in pain. Mr Muŋul̲purr handed Lena a slip of paper with his weight that morning written on it, having weighed himself on the renal unit's scales before Lena came to see him. Lena briefly reviewed the paper and then asked him, 'märi can I take off three litres today'? Mr Muŋul̲purr refused, and explained to me that patients weighed themselves and then nurses adjusted amounts of fluid to be removed from their bodies accordingly. 'I was a bit naughty last weekend, I drank too much (soft drink) at the football', he added, chuckling. Mr Muŋul̲purr sometimes experienced muscle cramps when there was too much fluid in his body or irregular amounts were removed. After setting up the dialysis machine, Lena inserted two thick needles with butterfly clips connected to plastic tubes into his fistula, which only seemed to cause Mr Muŋul̲purr a small amount of discomfort, and using a pump, sucked his blood into the tubes, and then quickly connected each tube to the dialysis machine. While Lena created a small pillow for the needles with a folded up bandage so that the clips wouldn't press against Mr Muŋul̲purr's arm and he instructed her how to arrange the tubes around his shoulder comfortably, Lena explained to me that the tube with the blue marker takes blood out and the tube with the red marker returns the blood to patients' bodies. Lena and Mr Muŋul̲purr then both explained the numbers on the screen of the dialysis machine to me, pointing out measurements of blood pressure, saline and time remaining. Lena asked Mr Muŋul̲purr, 'any tablets for you märi?', to which he agreed. After Mr Muŋul̲purr had taken his tablets and Lena had finished recording notes in

[21] The creation of a fistula involves the surgical joining of an artery and vein, usually in renal patients' arms, to provide an access point for dialysis.

his file and moved on to the next patient, Mr Muŋul̲purr explained, 'I call her gutharra (sister's daughter's child) because my brother adopted her. He already passed away'. I later learnt that Mr Muŋul̲purr's brother had also been a renal patient.

Conceptualisations of healthcare as a relational practice were evident amongst Yolŋu patients who drew some health professionals into relationships of fictive kin. This was by no means a practice adopted by all Yolŋu patients, but these relationships were recognised and extrapolated by other Yolŋu patients and family members, even after the death of the adopting patient. Processes of recognising fictive kin are not unique to Yolŋu (Sahlins 1974), and scholars of kinship studies have brought analytical attention to the constitution of kinship in the absence of biological ties through relations of care (Borneman 1997; Franklin & McKinnon 2001). As in Lena's case, adopted health professionals were often placed in fictive kin arrangements as the matrilineal grandchildren of patients, placing them within reciprocal relations of care in which intimacy between care-givers and care-receivers of different gender was permissible, as discussed in the previous chapter. In a discussion about the fate of patients without close relatives in Darwin, Helen explained, 'that's why some Yolŋu adopt nurses, because they are lonely', adding that patients who adopted staff were 'l̲aymaram' (experiencing relaxation or relief). Yinin remarked similarly, 'when you get to know a nurse after adopting them, it makes them feel part of the family. You think this person is treating me as family; they are no longer seen as a nurse. (Patients are) not feeling stressed'. Health professional adoptions represented attempts to create relations of care that were more amenable to Yolŋu.

Adopted health professionals who I spoke to agreed that their adoptions were not necessarily preceded by a long period of interaction with patients or an event that seemed significant, but perhaps by an expression of empathy or genuine regard, and often an attempt to use some Yolŋu matha words. However, adoptions seemed to create the potential for a close relationship to develop. Lizzie, a nurse, could only explain her patient's decision to adopt her as a granddaughter as taking place 'because I was caring for her', and was not able to offer further explanation. However, Lizzie's relationship with her patient and adopted grandmother led her to visit her patient when she was moved to palliative care, and after she passed away, to travel to north east Arnhem Land for the funeral at her adopted family's invitation.

Some health professionals agreed that their relationships with patients could mark renal wards and units as social spaces, and could impact on how care and treatment were provided. This was particularly the case for those with high amounts of patient contact, such as nurses, personal care assistants, Indigenous Liaison Officers and social workers; and for dialysis provided at the Nightcliff

Renal Unit, in which the patient cohort was more stable. Darren, one health professional, described how his status as fictive kin, and the expectations of care that it carried, could at once expand his workload while simultaneously making his job easier:

> *I mean for me, me personally, I was already adopted before I come into the renal role which makes it very difficult because I have an expectation* (placed on me) *that I will help a lot of the east Arnhem families, regardless of whether they're renal or not. And, they know me through their own story-tellings back in community so family are actually saying that there is someone here, they tell them who, what my skin name is, and then once they know me then they will always come to ask me so it escalates for myself because of that relationship but also it's made things a lot easier too because then there's a trust.*

Beyond those who were recognised as fictive kin, health professionals described their workplace as 'a community', and several described their relationships with patients as being 'like family'. Relating to patients 'like family' sometimes involved relationships with patients' extended families. This was not only because patients tended to have several relatives also receiving dialysis, and knowledge of how patients themselves related was essential for respecting avoidance relationships between patients in dialysis chair seating arrangements. It was also a product of the kinds of broader social issues that patients sought assistance with from health professionals. In renal units and wards, relational forms of agency were also embodied by health professionals. Patients who fostered relationships with health professionals and adopted them as fictive kin enabled staff to execute their work.

Care as personalised bodily knowledge

Yolŋu patients' expectations of care in healthcare included expectations that health professionals would acquire personalised knowledge of their individual bodies. For Yolŋu, blood is a sacred substance representing clan membership, and a dangerous substance when inappropriately tampered with. Yolŋu interlocutors considered dialysis a highly intimate form of treatment, as a treatment performed to blood and the insides of bodies. Yolŋu patients described expectations that health professionals would exercise particular care around blood and gain mastery over methods of inserting dialysis needles into patients' arms that caused patients minimal amounts of pain. For Yolŋu patients, transforming dialysis treatment into care required health professionals to become familiar with the idiosyncrasies of patients' bodies. Such expectations echoed the narrative of domestic care presented in the previous chapter, in which care was enacted as an intersubjective relation requiring attentiveness to patients' thoughts, feelings and bodily sensations. Helen was dissatisfied with the care she received from some renal nurses who caused her pain when inserting dialysis needles into her fistula because 'they don't know my body'. Long-term patients such as Helen and Mr Muŋul̲purr were sometimes asked by health professionals to share their experiences of dialysis with new patients.

Although some did seem willing to discuss their own experiences, they usually declined formal invitations on the grounds of only knowing their own bodies. Patients' expectations of care contrasted with biomedical concepts of bodily knowledge, in which the knowledge acquired from one set of bodies, such as through a randomised controlled trial, is transferable to other bodies.

Yolŋu patients' expectations of healthcare as invoking personalised bodily knowledge placed particular expectations on health professionals who were known to them. After Bu̲lanydjan commenced dialysis, surgeons in Darwin had tried to create a fistula in her forearm, but her vein was too thin and so a second surgery was attempted on her upper arm. In this second attempt, Bu̲lanydjan's surgeon made a mistake, resulting in a loss of sensation in her lower arm and the need for a third procedure which was successful but required a graft to be taken from her inner thigh. Bu̲lanydjan later found out that a medical student was responsible for the surgical error of her second fistula surgery and was angry, not only because a student had been allowed to 'train on (her) body', but also because another doctor who had worked in north east Arnhem Land and was at the time working at Royal Darwin Hospital, and who she had met before relocating to Darwin, had not been involved. 'He knows Yolŋu, he should have done the surgery', she said.

Approaching difference differently in therapeutic relationships

Contention between health professionals arose over appropriate ways to approach patient relationships in the presence of cultural alterity. It was not uncommon for Caucasian or Australian-born staff to voice concerns about staff from overseas, who were thought to have less awareness of Indigenous cultural difference, and who had perhaps not been socialised into certain ways of knowing Indigenous people. Some, such as Julie, articulated concerns about the proper performance of emotional labour:

> *I think the staff that we had last year, we had two staff that weren't um, Caucasian, and the ones that weren't Caucasian were very focussed on, do* (patient) *education. The Caucasian one was observing body language going, no enough, you know, enough's enough. So she picked up on how we did things and like you know, you can see when the patient's interested and had enough, you know…. We've also got a lot of different nationalities on the ward as well and they're very much, process, process, process.*

Some staff from overseas, however, found alternative ways to relate to their patients. Lena was a nurse from the Philippines and saw herself as sharing the experience of occupying a minority identity with her patients:

> *When I did my own research I found out that there's, um Indigenous, I'm not sure if Caucasians think like Indigenous people are, like minority group, but they feel that they are kind of minority group. And I myself, like for me I sort of kind of also belong to minority group here in Australia so it's, I feel ....good... sometimes feel more comfortable with them and because I'm not from here. And then, yeah we practice different culture from more, majority of group of Australians. I think Indigenous people feel the same way, yes.*

Lena's affinity with her patients sparked a curiosity about Indigenous cultures and led her to learn to speak some Yolŋu matha and Tiwi.

Indigenous health professionals from other parts of the Northern Territory and Australia, meanwhile, could often establish a relationship with Yolŋu patients through intermarriage, corresponding skin names or totemic connections. Indigenous staff and Indigenous patients who didn't immediately recognise one another in their first encounter appeared to proceed with caution, attempting to establish mutual acquaintances and making private enquiries in efforts to determine how they should relate to one another. One former Indigenous Health Worker[22] explained to me that establishing the nature of existing relationships between Indigenous staff and patients was important as the wrong form of behaviour or address according to the relationship could cause offense and could also impact other relationships. Healthcare as a relational practice was particularly foregrounded in relationships between Indigenous health professionals and Indigenous patients.

Contending values and expectations of health professionals' caring labour

Patients' expectations of health professionals' caring labour

In Darwin renal wards and units, care is a relational practice subject to disparate values and expectations. While both Yolŋu patients and health professionals attempted to establish relationships of care, they expressed divergent understandings of the obligations and responsibilities of care in renal services. Yolŋu patients and health professionals articulated different conceptualisations of the kind of person that the giving and receiving of care made one; and the kind of agency that giving and receiving care invoked.

[22]This term is adopted here in accordance with the way it is used by the Northern Territory Department of Health, to denote both Aboriginal Health Workers and Aboriginal Health Practitioners (Northern Territory Department of Health 2019a).

Renal services in Darwin offered care to patients in excess of basic medical treatment. A fleet of mini buses ferried patients between their accommodation and their medical appointments. Social workers and Indigenous Liaison Officers were employed at renal wards and units to assist patients to access housing and social security and to orient new patients to Darwin. A patient support service was funded through a combination of government and philanthropic funds and funds generated by Indigenous communities. Another NGO was contracted by the Northern Territory Government to provide renal patients, as a discrete group, with financial advice and assistance with accessing superannuation. The services provided to patients were such that some Department of Health staff were known to comment that 'renal is sucking us dry', displacing funding for other health services. However, beyond these institutionalised forms of care, patients often had high expectations of the caring labour of health professionals.

While patients who were undergoing crises or unable to relate to health professionals were at times incommunicative, I observed that patients who had a degree of familiarity with their health professionals, whether through adoption as fictive kin or simply through repeated interactions, seemed to be able to articulate their care needs and make requests for assistance. Almost all health professionals described receiving many requests from patients outside of their professional remit – assistance completing Centrelink forms in entirety, accessing bank accounts, finding relatives' phone numbers. One nurse recalled a patient calling her to request assistance with repairing his car. Therapeutic relationships of familiarity evidently invoked certain expectations of care amongst patients beyond those dictated by job descriptions and in policies and guidelines. Many of the claims made by patients of health professionals were no doubt a product of the complexities of applying to access government support services, health professionals' degree of expertise in street level bureaucracy and a lack of alternative sources of help in Darwin. Nevertheless, I contend that patients' relationships with their health professionals could enable requests to be made. Through relationships of care, patients enact relational forms of agency in healthcare contexts.

In the previous chapter, domestic care for renal patients within Yolŋu families was described as invoking forms of generalised reciprocity. I argue that Yolŋu patients placed care provided by health professionals known to them in a Yolŋu ethics of care of respect for the elderly and unwell. The caring labour of health professionals was understood by Yolŋu patients as evoking generalised reciprocity, in which reciprocation may be indirect and not subject to accounting. As Darren's comment in the previous section illustrates, health professionals who were known to respond to the requests of patients were likely to receive further requests, based on their relationship with patients. However, Yolŋu patients did not always consider the caring labour of health professionals to represent a

unidirectional transaction, as I will explore later in this chapter. The care of health professionals was understood by some as encompassed within broader relations of interdependency which encompassed health professionals' wages and the contributions patients made to initiating caring relationships.

Health professionals' responses to patients' expectations of their labour

Health professionals in renal services often displayed considerable generosity in the care they provided to patients. Virtually all health professionals with whom I conducted interviews described themselves as working beyond the strict confines of their job descriptions due to their commitment to their patients. Health professionals sometimes acted as advocates on behalf of patients within bureaucratic systems, for example in patients' dealings with Centrelink and the Patient Assistance and Travel Scheme. A nurse, although not on call, was willing to respond to after-hours queries from patients, while others discussed working unpaid overtime hours in order to ensure patients arrived at their accommodation safely after dialysis. One nurse described spiriting away sandwiches from the hospital's catering services for outpatients who had missed lunch.

Health professionals I spoke to were often deeply empathetic of patients' precarious circumstances and traumatic experiences of displacement. Health professionals' affective commitments to their patients could have consequences for themselves. Lena was visibly shaken and expressed regret when she and other staff were unable to help a patient who was homeless and was raped. Frequent encounters with the deaths of members of the renal 'community' were part of working in renal care, as related by two nurses, Julie and Maureen:

> Julie: *There will be some patients, you know that if some patients die you're going to, going to shed a tear.*
>
> Maureen: *Oh yeah there will be some.*
>
> Julie: *And it's like there's some patients, yeah I think I would actually be going to that funeral….Yeah cos just the other week we had one lady, a dialysis lady, her son died. Now he was on dialysis too. So we'd heard that this young feller was sick in ICU* (intensive care unit) *and all the patients came in and they knew that he was sick in ICU. …. He had actually died within the hour, so then we said to the patients, yeah he has actually passed away. Always funerals happening. Cos then just like an hour later we have the Mum came in cos the Mum had been with* (her son) *and then saw* (him) *deceased and then she came for her dialysis so then she walks in and it's like* (suppressing tears) *give us the tissues, because we all needed the tissues. Yeah. Just sad, sad.*

These affective commitments of health professionals to patients shaped the ways in which health professionals were drawn into providing care to patients.

Health professionals with whom I spoke usually associated their commitment to patients with ideals of professionalism and doing what was required to get their jobs done. However, some also admitted to being drawn into providing additional care through their relationships with patients. Lena told me that 'we just want to input more in their in the kind of like life, and we think that's why nurses here are willing to help patients, I think, because of our relationship'.

Health professionals also described refusing some patient requests, or gently referring patients to other sources of help. Policies and delegations could be easily bent to fulfil requests, and also easily invoked to refuse them – a point not lost on patients. A patient who requested his usual dialysis treatment be rescheduled so that he could attend a driving course in order to re-apply for his license was refused. The nurse's justification, that it would compromise his treatment, was met with a wry smile – dialysis was frequently rescheduled to accommodate patients' other medical appointments. Another member of staff declined a patient's request for a reference for his housing application on the grounds that 'I'm not really senior enough'. The patient later commented privately to me that 'she doesn't really want to help'. Some Yolŋu described both Indigenous and non-Indigenous health professionals who refused requests for help as *mukmuk* (externally controlled, or lacking in power and agency). Although *mukmuk* is a status usually attributed by Yolŋu to victims of sorcery, I understood attributions of *mukmuk* status to health professionals as a statement about staff who allowed themselves to become controlled by health bureaucracies. In a tacit acknowledgement that patient requests at times went beyond the institutional imperatives of healthcare systems, patients who made accusations about *mukmuk* health professionals positioned care-giving as requiring autonomy, agency and generosity.

Health professionals were at once engaged in boundary-making and boundary-crossing, attempting to pose limits to their relationships with patients while often becoming drawn into providing additional care. While health professionals imagined the limits to their relationships with patients in different ways, they were united in their representation of these demarcations as based on a logic of care and their own notions of professional commitment, as illustrated by Darren, who invoked the Closing the Gap policy framework:

> *Sometimes I feel that we have people that go over and beyond their role and that's not helping in any gap being changed. So you've gotta draw a line…. Obviously there's circumstances, you know, you need to consider the circumstances, but, I find myself going*

> *over and beyond a lot of the time and that's mainly around people's safety. People are homeless for a long period of time or for whatever reason and if they've got kids or anything like that I'm concerned, especially if they're not in their own community, so there's certain things that can be enacted to try and make sure that they're safe or I pull favours to get people home so, yeah no I don't see that being a burden, I see that as being, something that helps me, um, close the gap between the way that we... um... or should I say the way that our Aboriginal and Torres Strait Islander patients receive healthcare services because they already see someone in the system that they trust, so they can be more engaging in their presentations, so. I see it as a good thing.*

Darren implies that providing too much care for patients is unhelpful, reproducing patient dependency, while admitting that providing a high level of care is also sometimes necessary.

Darren's comments shows that health professionals' desires to provide substantive care to patients while imposing limits to their own labour could leave them feeling internally conflicted. Health professionals' relationships with patients and their attempts to provide substantive care could also bring them into conflict with other imperatives within health bureaucracies. Studies of the experiences of professional care workers show that they are often motivated by personal ethics of care, but emotional dimensions of care work are likely to escape codification and professionalisation, and may come into conflict with bureaucratised routines and expectations (Rummery & Fine 2012; Zelizer, V A 2009). The adoption of some staff as fictive kin, conflicting with expectations of professional detachment and equal treatment, were considered by some health professionals in Darwin renal wards and units to be an 'unprofessional' practice. Health professionals who took longer to perform their patient visits in the name of establishing mutual understanding with patients were liable to efficiency concerns from managers. The subjection of health professionals to divergent expectations of care by patients and the policies and protocols of renal services could lead them to express exasperation with both patients and other health professionals from outside of renal services who were perceived to take advantage of their greater commitment to patients. 'Dumping on renal' was a phrase that I heard repeatedly. While most health professionals I spoke to said they mostly enjoyed working in renal services, two young, junior health professionals ultimately resigned from their positions on the renal wards due to the irresolvable conflicts they saw themselves inhabiting.

Empowerment and responsibilisation narratives among health professionals

The substantial labour of care that health professionals provided to patients evidently troubled many of them. Care work often went beyond the boundaries of job descriptions, hours of work and policies and guidelines backed by the legal and institutional apparatus of healthcare. The liberal subjectivities of many health professionals were evident through their compassion for patients, and through their

problematisation of patients' high expectations of their care as excessive demands on their labour that were thought to sustain patient dependency. Through narratives of patient empowerment, health professionals recast their care work as assistance that would transform patients into agentive actors who were capable of managing their own health and other basic needs, and able to take control of their own dealings with government bureaucracies. Through the agency of health professionals in developing patients' biomedical health literacy, inducting them into the requirements and processes of government services and facilitating their participation in the formal economy, patients themselves would become independently agentive actors in control of their destinies. Health professionals' narratives of patient empowerment implied patient dependency was a temporary, transitional status, albeit one with unspecified timeframes.

'Empowerment' was the predominant discursive frame through which health professionals articulated the substantive care they provided to patients. Empowerment narratives embodied conceptualisations of care as a burden that worked to disempower patients and create dependency and inequality. Empowerment discourses invoked by health professionals envisioned the production of a particular kind of patient subjectivity, freed from reliance on health professionals. Many health professionals thought more empowerment was needed, embodying Tess Lea's remedial logic (Lea 2008). Several had ideas about how patient personal transformations could be achieved, which were often connected to patients' participation in productive roles. Darren discussed his ideas for achieving patient empowerment through the employment of some patients as advocates in renal services:

> *We can look at employing these past or present patients and their families to be active in their roles to support renal dialysis and we can actually empower them and make them feel a part of something rather than this burden in life which people feel when they're dislocated from their families and communities. If they can give back, everybody knows if you can give back that feels better than receiving so, and in culture itself, it's always making sure everyone's been looked after and everybody's sharing so that would support a proactive way of delivering service. But I think we need to actually look at what we're doing and try and ease that burden a bit, helping them feel like they're part of a community. And, and anyone that feels part of a community feels wanted and feels loved and appreciated so I think there's something that needs to be installed and what we deliver as a way of enacting people's positivity and empowerment.*

Darren suggests that equality can only be restored to therapeutic relationships through mutual transactions of labour. Other health professionals discussed further proposals for achieving patient empowerment, including a volunteer program in which established patients would induct new patients to Darwin, and a social enterprise dealing in Indigenous art. The nature of renal care as a process requiring the participation of both patients and health professionals was evident in relationships between staff and patients, such as that between Lena and Mr Muŋuḻpurr, and in the difficulty experienced by health professionals attempting to care for incommunicative patients.

However, asymmetries in therapeutic relationships were evidently problematic for some health professionals. As Kathryn Ellis (2005) has argued, social responsibilities in liberal democratic societies, premised on autonomy, contract and equality between parties, pose problems for asymmetric relations of care. Conceptualisations of care as a relation of mutual obligation, or a gift requiring direct reciprocation (Goodin 2002), contrasted strongly with the generalised reciprocities of care in Yolŋu domestic moral economies that did not entail direct or immediate repayment.

Empowerment was not the only discursive frame adopted by health professionals expressing desires for reciprocity in healthcare. A small minority invoked a frame of 'responsibilisation' in describing patients' obligations to care for themselves and manage their own personal affairs. Responsibilisation narratives recalled theories of neoliberal responsibility, in which rights and entitlements of citizenship must be earned through responsible behaviour, including by caring for oneself in particular ways (Hage & Eckersley 2012; Trnka & Trundle 2014). In this framing, patients were responsible for lessening health professionals' burden of labour by attending all appointments, following medical advice and taking medications. One interlocutor, Charles, described self care dialysis therapies, in which patients performed their own dialysis, in some cases in remote communities, as a manifestation of patient responsibility:

> *Some patient they like to stay in Darwin once they here, they don't want to take the responsibility of learning the dialysis and take the responsibility* (to) *look after themself. The other group, they want to go back cos they got strong relations back in the community and they want to contribute more to their community, or continue working. Some patients they don't have courage enough to, you know they're a bit worried more about the problems rather than, you know taking the challenge, they want everything done by their nurses. But some patients they're really keen to take that challenge and, or and that, hurdles, so once they done that they know what to do and how, what to expect and it gives them more confidence to act on it.*

In this narrative, patient responsibility was also positioned as a responsibility to society, enabling patients to resume productive roles.

While the frames of responsibilisation and empowerment implied differing conceptualisations of patient obligation, both ultimately envisioned healthcare as a relation of mutual obligation. Responsibilisation and empowerment frames differed in the emphasis placed on the agency of health professionals in the realisation of patient obligations. While responsibilisation invoked healthcare as an immediate transaction of labour, empowerment represented an exchange of labour in which patients recompensed health professionals by taking care of their own health and affairs in the future. While responsibilisation was reminiscent of the immediacy of market transactions, empowerment resembled a gift expected to be repaid at a later date. As David Graeber (2001: 219-220) has argued,

gift exchange and market exchange do not represent opposite poles of exchange theory, as both require reciprocation. Both frames ultimately referenced similar visions of self-contained, self-caring and self-managing, productive patients who minimised the burden they imposed on health professionals as restoring equality and patient agency to therapeutic relationships. These frames were also not necessarily competing poles of opinion, with some interlocutors invoking aspects of both discourses at times.

Despite health professionals' visions of empowered or responsible patients, paradoxically, many discussed adopting forms of paternalism in practice; and the strongest proponents of empowerment discourses were also those who appeared to be the most willing to care for patients in ways that modelled child-adult relationships. Some health professionals thought that the options presented to patients for receiving different forms of dialysis and for foregoing treatment should be constrained by an earlier assessment of the potential of patients to fully understand each option and its implications, although others disagreed. Patients were seen to have large amounts of spare time both during dialysis and on off-days, and staff debated how patient time should be used. Patients attending a patient meeting had their intake of tea monitored. Practices of paternalism could emerge from health professionals' attempts to manage cultural difference, in which they saw themselves as teaching patients about the processes and rationalities of government bureaucracies. Darren attributed patients' disempowerment to their lack of socialisation into the norms of healthcare, and described the fatherly role he occupied in relation to patients:

> *So those relationships are built on trust and respect but in saying that, you know, if they muck up they know I'm going to give them the cold shoulder, I'm going to explain to them that that's not appropriate, people are here to do their jobs. There has been many times when patient's been upset with nursing staff and I've had a quiet word with them and they come back and apologise to the nursing staff or doctors, so things happen, people in uncertain places and uncertain times can tend to snap and cos they don't feel like they're part of their own journey for one reason or another. And as long as they're explained appropriate behaviours and feel like they're a part of something then they can accept it….I consider it as a father you raise your child to understand right from wrong.*

I argue that paternalistic practices amongst health professionals could represent a response to patients who failed to comply with health professionals' conceptualisations of empowerment.

Health professionals admitted that ideals of patient empowerment were not always realised, and paternalistic practices sometimes resulted when empowerment failed. In health professionals' ethics of care, in which care figured as a gift requiring direct reciprocation, the inability or unwillingness of patients to repay social debts of healthcare were seen to give rise to social inequalities in therapeutic relationships in which patients figured as dependents. The failure of empowerment was often

attributed to patients. While some patients were described as being genuinely misinformed or confused about what to expect from healthcare, some health professionals also described tendencies amongst patients to occupy a habitus of 'learned helplessness' or a 'welfare mentality' or a lack of 'self efficacy': excessive requests made of health professionals were represented as a lack of patient power and agency and a product of dependency. While I never witnessed a patient rebuke a health professional for their paternalism, patients did at times, amongst themselves, parody health professionals who treated them as children.

Attempts to realise contending values of care through self care dialysis and professionalised Yolŋu carers

Thus far, I have described divergent values and expectations of care among Yolŋu renal patients and their health professionals. I have described patients' attempts to enact healthcare as a relation that expressed respect for the elderly and unwell, in which health professionals were known, were attentive to the idiosyncrasies of patients' bodies and were generous with their caring labour. I have also described health professionals' desires to foster patient independence in order to reduce patient dependency on their care, which, paradoxically, at times resulted in paternalistic practices. In this section I explore how divergent values and expectations of care played out through self care dialysis therapies and a proposal advanced by Yolŋu patients for the professionalisation of Yolŋu carers.

Northern Territory renal services offer self care dialysis therapies to renal patients. Through self care dialysis therapies, patients are trained to perform their own dialysis and sign a Memorandum of Understanding establishing shared responsibilities for their care with Northern Territory renal services. Patients undertaking self care dialysis are strongly encouraged to appoint a 'buddy', or carer, to assist them to perform their treatment. Patients can appoint one buddy to train alongside them to perform dialysis, and can also appoint a second buddy to receive training, but only after patients and primary buddies have successfully completed the training course. Patients and buddies performing self care dialysis in remote communities are supported by health professionals based in Darwin through regular phone calls and occasional site visits, and attend appointments in Darwin from time to time.

The Northern Territory Government, through its Renal Services Strategy, aimed to increase the number and proportion of self-dialysing patients (Northern Territory Government 2017b). All

accommodation needs of patients and buddies undertaking self care dialysis training in Darwin were paid for by the Department of Health for the duration of their training, sometimes for up to 18 months. As we will explore in Chapter Five, in the context of an extreme shortage of affordable accommodation in Darwin, this kind of investment is likely to have been highly valued by patients. The costs of self care dialysis treatment in the Northern Territory were 33% higher than urban models of nurse-assisted dialysis in patients' first year of treatment, after accounting for training and accommodation costs, but costs were recouped in subsequent years (Zhao et al. 2014). I argue that the significant investment made in supporting self care patients represented non-material forms of value that were seen to inhere in self care therapies as well as financial gains.

The value of self care dialysis, as articulated by health professionals, registered patient empowerment and responsibilisation discourses, as a mutual transaction of labour that promoted patient independence. Several concurred with Darren, who described self care therapies as the optimal form of treatment for end stage kidney disease after kidney transplants, as self care dialysis was seen to enable patients to escape the dependency and disempowerment thought to exist in therapeutic relationships and could be performed in some remote communities:

> *The models for renal replacement therapy is you know, transplant number one, obviously the best option, you get the best outcomes, you definitely feel the best, have the best health status. And option number two of self care which means that you do it in your own home, you're not dependent on a hospital, you're not dependent on a renal nurse and you're not dependent upon someone else's timeline.*

Health professionals often described themselves as advocates for self care dialysis, and generally only described the financial savings as a lesser benefit, although the budgetary implications were likely to have been foregrounded by other actors in healthcare systems. Health professionals continued to promote self care therapies following a policy change that enabled the expansion of remote dialysis services delivered by nurses and Indigenous Health Workers.

There were eligibility criteria for self care dialysis therapies that excluded some patients. For self care haemodialysis, eligibility criteria included a basic level of spoken English, English literacy, mathematics, dexterity and vision. For self care peritoneal dialysis, in addition to these criteria, an environment where standards of cleanliness and hygiene could be maintained was required, while previous abdominal surgery and scarred abdominal tissue could exclude patients. However, in conversations I had with health professionals, eligibility and choice often became muddied, as in the following examples:

> Edward: *We offer all modalities to everyone who is approaching end stage kidney disease and they can choose whichever they want, but some they get excluded either by choice or, by complex medical problems which make that a modality unsuitable for them.*
>
> Maureen: *There are some that have to go down the* (nurse-assisted) *haemo role, but it's still their choice. I still emphasise that even though I think they probably won't be able to do PD* (peritoneal dialysis) *I still send them to get assessment and education because it's their choice in the end.*

In these somewhat awkward narratives, patient choices are reified while the agency of health professionals and healthcare systems in shaping or constraining them falls to the background, echoing the problematics of agency discussed by Emma Kowal (2015). Empowerment narratives equate patient agency with patient independence, and assume that patients also ultimately desire greater levels of self sufficiency in healthcare. Annemarie Mol (2008) argues that a logic of patient choice casts marginalised patients as self sufficient subjects, without transforming the fragility of their lives, leading to poor care. Edward and Maureen's comments suggest that the possibility that some patients were either unable or unwilling to exercise the particular form of agency associated with self care needed to be countered with a logic of patient choice, avoiding the topic of patient dependency on health professionals' care.

Few patients in the Northern Territory undertake self care dialysis therapies despite the opportunity self care programs presented for patients to return to their communities. In 2017, less than 10% of renal patients in the Northern Territory were undertaking any form of self care treatment; and Northern Territory self care dialysis training programs have poor retention (Gorham et al. 2019). Of the 16 patients originally from Galiwin'ku receiving treatment in Darwin during my fieldwork, only two were performing self care dialysis, one of whom eventually abandoned it in favour of nurse-assisted treatment. The reasons cited by most interlocutors for not pursuing self care dialysis were a mix of fear, recalling Yolŋu taboos associated with blood, and personal limitations. However, many of those who cited personal limitations had good spoken English and English literacy, and had previously worked in positions that required them to use such skills, as teachers and interpreters for example. I contend that the fear and reluctance expressed by interlocutors were underscored by a treatment regime that did not reflect Yolŋu ethics and practices of care.

The problematic of self care dialysis for Yolŋu renal patients can be grasped through patients' own proposal for the caring labour of health professionals, in their own communities. Almost all of the Yolŋu patients I knew spoke of their desire to have young Yolŋu trained and employed to administer dialysis in north east Arnhem Land communities, some with specific family members in mind. Interlocutors still envisioned roles for (usually non-Indigenous) nurses in training and supervising

professional Yolŋu carers and in dealing with emergencies, but young Yolŋu would have the most prominent roles in the most intimate aspects of care. While patients admitted that Yolŋu administering dialysis would need to overcome fears associated with the handling of blood, they suggested their kin simply needed proper training. The proposal seemed to cannily unite empowerment discourses, productive roles and Yolŋu expectations of care.

Yolŋu interlocutors' proposal for the employment of younger kin in renal services enacted caring labour as a representation of respect and as a relation between generations. Some, such as Helen, said such arrangements would reinforce the obligations of younger relatives to 'look after (their) grandmother'. The families of renal patients did not always fully understand their conditions or their care needs, especially when they were geographically separated by the current requirements of dialysis, she said. 'People wonder why we're on dialysis, dead', she told me, implying that patients' kin in their communities were liable to forget about them, treating patients as if they no longer existed. Helen thought that those who would be trained to perform dialysis should be different individuals to those engaged in domestic forms of care, who already had significant claims on their time. Her desires recalled Yolŋu conceptualisations of the responsibilities of the elderly to care for the young, not through physical labour but by considering the needs of younger relatives performing physical care work.

In describing desires to see young Yolŋu perform dialysis, Wapiriny placed healthcare within a broader frame of interdependent relations, emphasising that health professionals are remunerated for their work. 'People are making money from my body', he complained, suggesting that unfamiliar health professionals could exploit patients, and in doing so, drawing a sharp contrast with health professionals' narratives that attributed dependency to patients. 'If Yolŋu take on needling they lose their job', he added. Bulanydjan, who had performed self care dialysis for a period, until her arthritis prevented her from administering needles, echoed Wapiriny, pointing out that self care dialysis was not remunerated in the same way as care provided by health professionals. Bulanydjan implied that nurses' wages created certain obligations of care:

> *I said to them 'why we doing this machine if we not paid for this work'? We on whatever special name in hospital or from Centrelink* (Disability Support Pension). *But this is you mob, for you nurses job, you can do this one, you know'.*

The proposal envisaged interdependent relations between Yolŋu providers of renal care and Yolŋu patients who enabled their remunerated and socially valued work. The high turnover of health professionals in Darwin and north east Arnhem Land, who had limited ability to develop relationships

with patients, did not go unnoticed by my Yolŋu interlocutors and was also addressed in their proposal for young Yolŋu to take on aspects of renal care.

Marcia was a young patient in her 30s who was likely encompassed in different expectations of care to older interlocutors. Marcia had commenced dialysis when she was 15 and was undertaking self care dialysis in Darwin. She described enjoying the flexibility that accompanied self care treatment regimes and the opportunity to develop a detailed knowledge of her condition, discussing her ability to perform her own treatment and record her own notes in her patient record with pride. Marcia, however, continually emphasised the helpfulness of nurses, who were never far away in case something went wrong. She commented repeatedly, 'home training dialysis – that's where you will find help and freedom', expressing her agency in performing her own treatment as enabled, in part, by the care of nurses. Her comments echoed the perspectives of other interlocutors discussed in Chapter Two, who conceptualised personal power and agency as produced through social relations.

The kind of empowerment encapsulated in Yolŋu interlocutors' proposal, however, was evidently not the kind envisioned by health professionals or within health bureaucracies. Their proposal presented a series of complexities of legality, ethics and governance for healthcare planners. While administering one's own treatment is encouraged, I was informed by a senior staff member, administering treatment for others invokes an assemblage of medical boards, accredited training, professional registration and remuneration. Although Indigenous Health Workers have been combining familial and professional responsibilities for several decades, in the Northern Territory their competencies do not include renal care; and their numbers have been declining for some time (Gorham et al. 2016; Human Capital Alliance 2009). For my interlocutors' proposal to become a reality, a new profession would need to be created and a new accredited training course established; or renal care units added to Indigenous Health Worker courses and existing Indigenous Health Workers re-trained (Gorham et al. 2016).

While it was already possible for Yolŋu carers to learn how to administer dialysis as buddies in self care dialysis regimes, few had taken up the non-remunerated roles that included little prospect of respite. Although self care therapies were attributed value in empowerment narratives as processes through which patients would become independent, self care therapies relied on familial relations of care. Buddies administering dialysis treatment to a family member, a renal service manager told me, were not remunerated because they were considered to be providing a form of treatment 'more like self care'. Buddies were also sometimes ineligible for the Carer Payment, a social security payment paid to some Australians performing domestic care, and patients performing self care were often considered

ineligible for the Disability Support Pension, having also been positioned as independent in social security systems. Several Yolŋu renal patients and their carers had commenced the self care training course before dropping out of the program, and a few others had gone on to perform self care dialysis for brief periods of time, before abandoning the program and returning to treatment provided by nurses. Former buddies tended to describe the long hours of work and the immense responsibility of handling blood in self care treatment regimes as overwhelming. In comparison to the interdependent, collective and more widely dispersed practices of care amongst Yolŋu described in the previous chapter, self care dialysis was likely to prevent buddies from attending to the needs and events surrounding other kin, as well as from participating in full time paid work. As with health professionals, for Yolŋu buddies, there were also limits and boundaries of care, beyond which interdependencies could become strained and carers could feel exploited. Northern Territory self-care dialysis programs neglect the social and material needs of carers and inhibit the capacity of patients to provide for their kin, transforming interdependent relations and collective practices of care in Yolŋu families into the dependency of patients on one or two buddies.

As scholars of the public health self care movement have argued, self care regimes, although premised on (neo)liberal values of atomic individualism, invoke familial relations of care and non-liberal practices and relations of caregiving (Chudakova 2017; Marsland & Prince 2012; Seligman et al. 2014). My interlocutors also show that public health self care regimes, premised on narratives of individual self sufficiency and self-realisation, can inhibit non-liberal forms of agency. Despite the valorisation of caregiving in Yolŋu families, and the possibilities for agency and autonomy within a Yolŋu ethics of care, there are low levels of self care dialysis adoption and program retention among patients and their carers. In the Northern Territory, self care dialysis programs require Yolŋu carers to subject themselves to social roles and norms in the service of biomedicine, while failing to recognise care as a relation of social and material reciprocity, constituted through interdependency and generalised reciprocity. Self care programs rely on yet also compromise the social roles and interdependent relations among kin that enable caregivers and patients to act on the world in ways meaningful to them, through relational modes of agency, in pursuit of self-realisation and basic material needs.

Relations of care and co-contribution are essential to the successful provision of biomedicine in renal services. As scholars of care have argued, state-sponsored healthcare invokes relations of reciprocity between patients, and health professionals or states (Andaya 2009; Kyeong Seo 2016). Both the practices of care in families performing self care dialysis, and the relations between health professionals and renal patients, are integral to the operation of dialysis. While other scholars have described healthcare as producing social and financial indebtedness among patients, and as

reproducing social inequality between patients and health professionals, I have shown that contributions to relations of care and to biomedicine can take on a variety of practices and forms, beyond the funding of healthcare services and the physical labour of health professionals. Patients' contributions can include participating in one's treatment, the fostering of relationships, the adopting of fictive kin, and the jobs and wages of health professionals which are indirectly created by patients' needs. My Yolŋu interlocutors illustrate that healthcare can be understood as a relation of care and of generalised reciprocity, and through a comprehensive understanding of care, healthcare need not be understood as rendering patients passive recipients.

Conclusions

In this chapter, I have explored how the care for Yolŋu renal patients is practiced and valued in renal services. I have shown that in the renal wards and units in Darwin, healthcare emerges as a relational practice. Conceptualisations of care practiced, embodied, and narrated by both renal patients and their health professionals escaped the reduction of care to biomedical markers and monetary forms of accounting, but expressed contending values and expectations of the labour of health professionals and familial carers. While a cultural awareness framework attempted to manage healthcare in the presence of cultural alterity, it did not contemplate care as a cross-cultural category - albeit one understood and practiced in disparate ways.

In this chapter, I have explored the interaction of disparate values and expectations of care among Yolŋu patients and health professionals. Yolŋu patients attempted to reconfigure relations of care and to realise social value through renal services, placing healthcare within a Yolŋu ethics of care that expresses respect for the elderly and unwell. Expectations of healthcare in which health professionals are known, acquire a specific familiarity with patients' bodies and can be relied upon for generosity in their caring labour, shaped renal patients' engagements with health professionals. Notably, the commodification and professionalisation of healthcare through the remuneration of health professionals appeared to be understood by patients as placing patients and health professionals in interdependent relations; and appeared to be only thought of as a corruption of care in the absence of relationality. Patients' proposal for younger relatives to be trained to administer dialysis, through the professionalisation and remuneration of domestic relations, was advanced as a strategy for reinforcing interdependent kinship obligations through biomedicine. For Yolŋu patients, power and agency within therapeutic relationships, registered through the capacity of patients to participate in

their care and make requests of health professionals, were a product of relationality. I return to the topic of the capacity of Yolŋu to exercise power and agency through healthcare in Chapter Eight.

Responding to Yolŋu patients' attempts to enact a Yolŋu ethics of care through healthcare, health professionals were often generous in the care they provided to patients but ultimately sought to cultivate greater patient independence. In health professionals' narratives, healthcare predominantly figured as a gift that produced undesirable dependency and inequality in therapeutic relationships. Health professionals' narratives expressed liberal values that at times could slide into a neoliberal logic of responsibilisation. Equating patient agency with patient self sufficiency, health professionals imagined that equality and patient power would be restored by reducing patients' reliance on their labour. While also describing a need for positive relationships with patients, health professionals were desirous of relationality that entailed mutual obligation, or direct reciprocation. In health professionals' narratives, reciprocation would take place through the labour of patients who cared for themselves in ways that reduced health professionals' workloads.

Self care dialysis was promoted by health professionals as a form of treatment thought to advance patient empowerment and independence. Yet self care therapies, like patients' proposal for the professionalisation of carers in renal services, rely on familial relations of care. The expectations of care contained in self care dialysis regimes that offer no remuneration or respite to carers do not reflect Yolŋu care practices or expectations of kinship, and may alter or strain relations among kin, as evinced by low rates of uptake and high rates of dropout. In this chapter I have drawn on and extended scholarship on care in healthcare, illustrating that healthcare may also be constituted through reciprocities of care, which may invoke formal employment responsibilities and entitlements including the remuneration of health professionals. I have also contributed to the scholarship of self care in public health, demonstrating that paradoxically, in some circumstances, self care regimes may rely on yet also compromise non-liberal practices of care and non-liberal forms of agency.

Self care dialysis provides an instance of the reliance of the state on familial relations of care to achieve a particular policy agenda. In the following two chapters I further explore how social policy agendas rely on relations of care in Yolŋu renal patients' families. I consider the interaction between values and practices of care in Yolŋu domestic moral economies with values of self care and self sufficiency and policy measures characterised by paternalism in housing and social security policy.

Chapter Five
The 'visitor problem': interdependencies of care and shelter in urban social housing

'We never really leave home', Mr Muŋul̲purr commented, explaining the co-residence of intergenerational Yolŋu family groups. This was an observation I'd heard numerous Yolŋu interlocutors make on different occasions. Practices of physical mobility, noted in earlier chapters, are a visible feature of Yolŋu sociality. Mr Muŋul̲purr's intention, however, was to contrast Yolŋu practices of co-residence and economic interdependency between generations and over the lifecourse to rites of passage in Western societies of moving out of one's parents' home and establishing financial independence. He told me, 'on your side you're independent, own house and job'. Waymamba, who was also present agreed, adding, 'you're independent, different, living away from your family. You still have family and friends but you're isolated'. For Mr Muŋul̲purr and Waymamba, housing could represent the financial independence of nuclear families in Western societies, as well as material interdependencies among Yolŋu kin.

Housing as a site and resource of care

In the following two chapters, I explore material dimensions of care for Yolŋu renal patients through the articulation of Yolŋu domestic moral economies with the provision of care through social policy. As discussed in the Introduction, care can be considered to comprise interlocking material and immaterial relations through which people understand what they owe one another and themselves. As Viviana Zelizer (2009) has argued of contemporary Western societies, the complexity of familial relations of care lies in the intertwining of social ties with economic activity or, put differently, processes of production and social reproduction. While a material register of care provides a critical

vantage point on care relations, it is one liable to be overlooked in romanticised accounts of care that abstract care from economic relations.

The present chapter attends to houses as sites and resources of care. As a locus of practices of sheltering, dwelling, belonging and domestic labour, housing constitutes a critical material dimension of caring relations (Smith 2005). Anthropologists have often approached housing and practices of dwelling as a mode of social organisation through which residents' responsibilities to one another are constituted (Alexander et al. 2018; Silverstein 2004). Housing patterns the social and economic organisation of care work and is deployed in its governance (Mee 2009; Power & Mee 2019). Care may be governed through housing to produce particular kinds of citizens, communities and nations (Alexander et al. 2018).

Houses, as sites and resources of care, are heavily implicated in Yolŋu domestic moral economies. Housing is also implicated in relationships between Yolŋu families residing in social housing and the state. In this chapter I consider how care is practiced and valued in Northern Territory housing policy, and how housing is mobilised in Yolŋu domestic moral economies to realise Yolŋu values and practices of care. I explore the interaction of disparate values and practices of care in housing in Northern Territory housing policy and among the families of Yolŋu renal patients. I describe the politics of care that plays out through the allocation of scarce public housing properties to renal patients, through public housing tenancy agreements and through the relegation of some renal patients to other more precarious forms of accommodation. I examine contention over the presence of visitors between Yolŋu and housing officials, or what I term the 'visitor problem', through which disparate values and practices of care were brought into relief. I argue that housing policy frameworks rely on Yolŋu practices of care and of sheltering kin, often in unacknowledged ways, while at the same time working to marginalise them.

In the following sections I discuss the ways in which care is governed through social housing in the Northern Territory, and my approach to understanding Yolŋu practices of dwelling. Drawing on interviews with staff from the Northern Territory Department of Housing, Local Government and Community Development (known colloquially as Territory Housing), I then discuss the allocation of public housing to applicants in Darwin. I consider the values and expectations of care in housing and the legibility of housing need in Northern Territory housing policy and practices. I go on to present a Yolŋu renal patient's narrative of values and practices of care in public housing in Darwin. I discuss the politics of care that emerges through the interaction of Yolŋu values and practices of care in housing with Northern Territory housing policy agendas. I also briefly discuss renal patients' experiences of

supported accommodation and private rental properties, through which a similar politics of care plays out.

The governance of care through social housing in the Northern Territory

Across developed Western states, the restructuring of social housing programs embodies an interplay of neoliberal and paternalistic philosophies of care. In social housing programs, both domestic care and housing have been repositioned as an individual responsibility (Fennell 2015; Power & Bergan 2018). The problematisation of social housing dependency as a moral and psychological failing of residents has informed neoliberal policy, financial and organisational reforms and social housing disinvestment (Alexander et al. 2018). Social housing programs have attempted to shape tenant conduct according to norms of self care through the conditionality of tenancies (Habibis et al. 2013; Power & Bergan 2018). Through a paternalistic 'politics of behaviour', the governance of housing increasingly encroaches on the domain of culture and differentiated modes of dwelling, attempting to manage tenants' responsibilities to others and themselves (Flint 2003, 2004).

The governance of care through social housing in the Northern Territory reflects, in part, a local articulation of neoliberal housing restructuring. In contemporary times, the housing exclusion of Indigenous Territorians in urban areas has largely been a product of a lack of affordable private rental properties and significant shortages of social housing (Anglicare Australia 2018; Taylor 2007). Declining public housing stock in Darwin has resulted from dilapidated properties not being replaced; the shifting of public housing stock to NGOs and to an affordable housing program providing subsidised accommodation to low to medium income workers in key industries; and sales to private developers (Northern Territory Department of Housing and Community Development 2018a; NT Shelter 2016). Private rental properties have increasingly been positioned in Northern Territory housing policy as a means for Territorians with low incomes to escape housing dependency. Territory Housing offers interest-free loans to assist low income private rental tenants to pay bond, and were also developing private rental 'wrap around services' in their new strategy to encourage public housing tenants to take up private rental leases (Northern Territory Department of Housing and Community Development 2018a). The Northern Territory Government's Homelessness Strategy aims to reduce rough sleeping and other forms of homelessness in urban areas, including through a long-

term plan beyond the life of the strategy to increase access to private rental, affordable and social housing, but contains no new investment in social housing (Northern Territory Government 2018b).

Historic continuities exist, however, in paternalistic attempts to produce particular kinds of citizens through Northern Territory housing policy and their application to Indigenous Territorians. Historically, housing policies in the Northern Territory have been instruments of colonisation, implicated in processes of dispossession, segregation and assimilation (Markus 1990; Read 2000; Wells, S 1995). From the period of early European settlement until the mid 20th Century, Indigenous Territorians were prohibited from residing in urban areas, while authorities attempted to gradually institute sedentary ideals through various forms of institutionalisation (Read 2000). Mid-20th century 'transitional housing' programs designed to house Indigenous people, affording structures of corrugated iron and canvas without running water or ablutions, embodied a paternalistic philosophy of inculturating sedentarisation and other Western norms of dwelling through a staged approach (Ross 2000).

A politics of behaviour continues to play out in the homes of Indigenous residents of public housing in urban areas of the Northern Territory. Approximately 72% of Northern Territory social housing properties are occupied by Indigenous households (Australian Bureau of Statistics 2016a) [23]. The contemporary governance of urban public housing embodies a philosophy of care that is at once neocolonial and neoliberal, premised on sedentarisation and self care. A politics of behaviour plays out in public housing through both the allocation of properties and through the governance of residents' conduct in tenancy agreements. Public housing is conceptualised in policy frameworks as a resource of self care, promoting hygiene, sanitation, cleanliness and sobriety. Self care, understood as the responsibilities of tenants for their own wellbeing and the wellbeing of a nuclear family, is governed through restrictions imposed on numbers of residents and visitors, two week time limits on visitors and bans on consuming alcohol inside properties (Northern Territory Department of Housing and Community Development 2016). One housing official explained to me, 'housing is a health service'. A sedentary bias in the governance of public housing is evident through application processes that require ongoing residence in a single location and pose limits on absences from properties (Northern Territory Department of Housing and Community Development 2015, 2016).

Renal patients relocating from remote Northern Territory communities to urban centres generally leave public housing, which is often the only form of housing available in remote Indigenous

[23] The Australian Bureau of Statistics defines an 'Indigenous household' as a household in which one or more members identifies as Indigenous.

communities. Remote public housing, however, is subject to different forms of governance. Remote public housing rent is calculated at lower proportions of income and tied to lower rates of urban private market-based rent (Northern Territory Department of Housing and Community Development 2017). Through the legacy of previous administration of remote housing by the former Aboriginal and Torres Strait Islander Commission and local Indigenous housing associations, power is wielded differently through remote housing. Housing Reference Groups comprised of local elders advise on the allocation of remote public housing, although decision-making power is ultimately vested in Territory Housing officials. Territory Housing officials suggested that those without strong claims of connection to a community would be unlikely to be allocated a house there. There are some differences in eligibility criteria for priority public housing. Residents of remote communities could be prioritised for public housing based on their participation in paid work in the formal economy, while urban dwellers could be deprioritised for it: the moral legitimacy of claims to housing were premised on different logics of mutual obligation and need. Visitors residing in remote public housing were permitted to stay for up to six weeks, however caps on the numbers of residents and visitors and the length of visitors' presence do not appear to be well enforced. A remote housing manager with 6 years' experience told me, 'we've never evicted anyone… I don't think it's something that's been tested yet'. The leniency of housing officials in remote areas may be in part a product of questions about their legitimacy over the administration of housing on land on which Indigenous land rights or native title are often recognised, and in the context of even longer waiting lists and higher rates of overcrowding in remote areas (Australian Institute of Health and Welfare 2015b; North Australia Aboriginal Justice Agency 2016).

Approaches to housing amongst Indigenous Australians: housing alterity and housing disadvantage

Studies investigating access to housing amongst Indigenous Australians are complicated by the intersection of Indigenous disadvantage and cultural difference in practices of dwelling. Research investigating housing for Indigenous Australians has predominantly adopted one of two approaches, exploring ways of occupying domestic space; or investigating housing policy and governance arrangements[24]. Few studies exemplify both traditions, although Christie et al (2013) and Fisher (2015)

[24] Sanders (2008) describes this literature as mapping onto one side or another of a tension in Indigenous affairs between equality and difference, with equality-oriented literature focussed on access to housing and difference-oriented studies exemplifying a culturally appropriate housing agenda. In a literature review, Long

are exceptions. Scholars pursuing the former approach have argued that Indigenous practices of dwelling, including the co-residence of multiple generations and mobility between dwellings, are essential to ongoing enactments of kinship bonds, but poorly recognised in publicly-funded housing programs (eg: Birdsall-Jones & Christensen 2007; Daly & Smith 1999; Day 2000; Fantin 2003; Memmott & Chambers 2003; Musharbash 2008). Indigenous scholar Jenine Godwin Thompson (2014) describes such practices as enactments of Indigenous conceptualisations of health that require the ongoing maintenance of relationships with kin and country. Others investigating the policy and institutional context of Indigenous Australians' housing find housing programs are poorly designed and resourced to meet high levels of disadvantage amongst Indigenous Australians (eg: Habibis et al. 2013; Holmes & McRae-Williams 2008; Neutze 2000; Prout Quicke & Green 2017; Sanders 2005; Taylor 2007). A growing body of scholars who have placed the living arrangements of Indigenous Australians in biomedical regimes of value, by examining connections between housing and biomedical health, have tended to broadly support the conclusions of other research adopting a housing disadvantage orientation (eg: Bailie & Wayte 2006; Dockery, M et al. 2013; Pholeros et al. 1993; Thomas, D & Stevens 2014).

In this chapter I resist the academic division of labour in Indigenous housing research. I show that the governance of social housing and Yolŋu practices of dwelling are heavily intertwined. I argue that the politics of housing distribution cannot be disembedded from the social relations in which it is situated. Relations inside houses between kin, and relations between Yolŋu households and public institutions existing outside of houses, are heavily interrelated and interdependent.

Urban public housing distribution through the construction of legitimate housing dependency

Renal patients displaced to Darwin for their treatment were likely to contend with housing precarity. In 2018, a rental affordability report found that at the time of research, there were no private rental properties that were both affordable and appropriate in all of the Northern Territory for recipients of almost all categories of social security (Anglicare Australia 2018)[25]. During my fieldwork, the wait list for a one bedroom public housing unit in Darwin climbed to 6 – 8 years (Northern Territory

---

and colleagues offer classifications of Indigenous housing research as 'micro level' (living environments) and 'macro level' (policy agendas) (Long, S et al. 2007).

[25] The report's methodology took into consideration the eligibility of low income private rental tenants for Rent Assistance.

Department of Housing and Community Development 2018b). While most social housing in the Northern Territory is public housing (Northern Territory Department of Housing and Community Development 2018a), NGOs administering other forms of social housing also reported lengthy wait lists for their properties to me. Daphne Habibis and colleagues (2011) report that Indigenous renal patients are at high risk of homelessness, and a study of Indigenous renal patients in Alice Springs estimated 15 – 20% had no secure housing (Cass, A, Brown, et al. 2011). Average survival rates of Northern Territory dialysis patients, at 6 years (You et al. 2015), were shorter than public housing wait lists, and I was aware of at least one Yolŋu patient who had died while waiting to be housed. In this section, however, I examine how extreme housing shortages animated a particular construction of housing need that could grant renal patients greater access to public housing than their kin. I argue that care was valued and practiced by Territory Housing in a way that allocated scarce public housing to applicants who were considered to be legitimately housing dependent, such as renal patients.

Faced with large numbers of public housing applicants and low levels of vacant public housing stock, Territory Housing staff had a difficult task in determining how public housing allocations should be made. Public housing applicants were required to complete application forms, and those who fulfilled eligibility requirements were subsequently interviewed by Territory Housing staff. Applicants considered to require urgent public housing could be placed on the priority public housing wait list and have their housing applications fast-tracked, based on eligibility criteria associated with their risk of homelessness, the presence of serious medical or social problems and their subjection to domestic or family violence (Northern Territory Department of Local Government Housing and Community Development 2020). However, applicants eligible for priority public housing still waited 3 – 4 years to be allocated a house, on average (Northern Territory Department of Housing and Community Development 2018b). Applicants placed on the priority public housing wait list had their housing needs further assessed and ranked by housing officials. Territory Housing officials who ranked claims expressed a tension between the universalising logic of making housing allocations based on standardised criteria, and consideration of clients' personal circumstances in interviews with me. I argue that this was a tension that they resolved through the deployment of the unofficial categories of legitimate and illegitimate housing dependency.

The allocation of priority public housing was likely to be influenced by applicants' sobriety, sedentarism and the degree to which their circumstances were not of their making. Layla, a housing official involved in assessing priority public housing applications, told me that applicants assumed to be capable of paid work in the formal economy, such as younger men, were less likely to be allocated housing rapidly, even if they were not employed at the time of application. Emily, another housing

official involved in allocating properties, explained to me that applicants who could demonstrate a 'quiet' disposition were more likely to be allocated housing. When tenants attracted complaints from neighbours about noisy behaviour, she explained, houses and units could be labelled as 'sensitive properties'. Irrespective of whether complaints were seen to be legitimate by Territory Housing staff, staff attempted to make future allocations of 'sensitive properties' to 'somebody… that won't create issues', transforming 'sensitive properties' into 'quiet properties' by making future allocations to 'a different demographic'. Emily described the work of judging the ways in which future tenants may inhabit public housing as taking place in interviews, including in response to questions about applicants' drinking habits. Making housing allocations based on assessments of applicants' dispositions was justified by Emily through a paternalistic concern about protecting public housing tenants from racist stereotyping by neighbours.

Public housing allocation procedures also exhibited a sedentary bias. Public housing wait lists were specific to towns and communities across the Northern Territory, and remaining on a particular wait list required frequent confirmation by applicants of their residence in the town or community and their intention to remain on the list. Territory Housing imposed limits on absences from houses and prescribed acceptable reasons for long absences that emphasised inter-state, but not intra-Territory travel (Northern Territory Department of Housing and Community Development 2015). Priority public housing, I argue, was allocated through the construct of legitimate dependency, or the social category that Michael Katz (1989) termed 'deserving poor', to applicants whose need for public housing could be attributed to personal circumstances they were not held responsible for. As Katz argued, public discourse that gives rise to categories of deserving and undeserving poor in welfare programs can transform questions about the distribution of resources to matters of morality and behaviour.

Categories of legitimate and illegitimate dependency deployed by Territory Housing served to distinguish renal patients from other migrants from remote Indigenous communities, and especially from *longgrassers*. A highly stigmatised term, *longgrasser* is applied to itinerant Indigenous people originally from remote communities who sleep rough in urban areas of the Northern Territory and who are reputed for their binge drinking (Holmes & McRae-Williams 2008; see Chapter Two). Both renal patients and *longgrassers* could be considered to be at risk of, or actually experiencing, homelessness, fulfilling priority public housing criteria. In contrast to *longgrassers*, however, renal patients were also considered eligible for priority public housing as a result of their medical conditions, while the demands of their treatment prevented physical mobility. Renal patients could be more readily categorised as legitimately dependent and were more likely to adhere to the sedentary requirements of Territory Housing wait list procedures. Some reported waiting only a few months to

be allocated public housing. The unofficial deployment of categories of dependency by Territory Housing did not work to allocate public housing to applicants with end stage kidney disease rapidly in all circumstances, however, and some of the renal patients I knew had also spent periods of time sleeping rough. Nevertheless, a senior housing bureaucrat told me that if renal patients were sleeping rough, 'something has gone wrong'. As moral anthropologists have argued, as access to social welfare becomes less universal and more subject to medical, legal and scientific criteria, value inheres in physical illness; but not necessarily in other form of marginalisation (Fassin 2009; Petryna 2002; Rose 2007).

Categories of legitimate and illegitimate dependency could operate through an affective register. Considerable compassion existed amongst service providers and policymakers for those who could be categorised as legitimately dependent, such as renal patients. One renal patient recounted that she and her late husband had waited for two years for public housing. After my interlocutor's husband wrote a letter to a Member of Parliament complaining about the delay and the poor conditions in the hostel in which they and children in their care were living, the family were allocated a three bedroom house within 6 weeks. Although the interlocutor was relieved to secure a house, she and her husband could not afford the $785 bond. She recalled, 'I tried really hard, rang family, all of them refused. My husband went to the casino for money but nothing. There were only two days left (until the tenancy agreement was to be revoked) and I went to a building, for overseas, refugee mob'. The agency initially refused to help her, citing her lack of fulfilment of the program criteria, but she protested, 'I'm a refugee from the longgrass'. The manager continued to refuse her assistance, but in the car park quietly handed her the money required for her bond. It was 'free money', she said, she was not asked to pay it back.

In claiming access to housing and other services that were mediated by assessments of 'legitimately dependent' status, renal patients were supported by moral publics that drew in health professionals, researchers, lawyers, artists and others, who at times positioned renal patients' displacement as creating a social debt they were owed by society. Following the death of the internationally acclaimed Yolŋu recording artist Dr G Yunupiŋu in Darwin, from complications of end stage kidney disease and in circumstances of homelessness, at least 24 stories about the plight of Indigenous Australians receiving dialysis appeared in local and national media, serving to draw in others to the cause. A poster at my local physiotherapy clinic advertised raffle tickets to raise funds for dialysis machines in communities in remote Central Australia. The poster represented public sympathy for renal patients and public recognition of unaddressed healthcare needs.

Renal patients, however, could easily slip into the category of illegitimate dependency, as people who had travelled from remote communities to Darwin. Interlocutors attempted to combat this slippage, sometimes pointing out that dialysis required sobriety, and implying that renal patients inhabited a different form of subjectivity to drinkers. At multiple times during my fieldwork, when I took Yolŋu interlocutors to parks and reserves around Darwin and we shared food, police or park rangers sidled up to us to inspect what we were doing, checking whether alcohol was being consumed. Each time, they were met with exclamations from my interlocutors, 'we're renal patients here!' An application form for social housing properties administered by an NGO that Mr Muŋul̲purr asked me to assist him to complete contained implicit narratives about the pathology of homelessness. Both of us were uncertain about how to respond to questions about the presence of a 'case management plan' and 'personal goals/objectives'. There was also a box to tick for arranging night time access for correctional services staff. In response to each question, he repeated, 'tell them I'm a renal patient!'

Categories of legitimate and illegitimate dependency could work to pit the housing and other needs of renal patients against other Indigenous people also suffering from homelessness and housing insecurity in housing programs. Some local alcohol and other drug service providers suggested that the claims of renal patients to housing could lead to drinkers, who were also facing homelessness, and who may have been waiting for housing for longer, being further deprioritised for public housing by Territory Housing. An advocate for Indigenous women experiencing domestic or family violence thought that women's shelters may legitimately de-prioritise renal patients experiencing intimate forms of violence when allocating emergency shelter as renal patients had many other advocates they could turn to for help. However, distinctions made by Territory Housing and other local service providers between renal patients and others were not distinctions that Yolŋu families themselves were likely to make.

The unofficial categorisation of priority public housing applicants by Territory Housing as legitimately or illegitimately housing dependent represented an attempt to house the neediest applicants in scarce public housing. The deployment of such categories, however, could work to create material inequalities between those whose housing precarity was rendered morally legitimate, and others also facing insecure housing or homelessness. For some Yolŋu, this was likely to translate to differential access to public housing between renal patients and their recognised carers, and unrecognised carers and other kin. After one Yolŋu interlocutor with end stage kidney disease passed away, his co-resident carers and kin were evicted from his public housing unit, which was reallocated to others on the wait list. Julie Finlayson (1989) and Fay Gale (1981) have argued that gendered conceptualisations of legitimate dependency in public housing programs work to produce female-headed households and

unequal access to housing among Indigenous women and Indigenous men, while Finlayson also argued that material inequalities don't translate to altered social status nor prevent men from making claims on women's resources. A similar phenomenon appears to operate in public housing in Darwin with regards to renal patients. Yolŋu renal patients, male and female, were often considered to be the heads of their households, and houses were often referred to in relation to their heads – for example, 'Helen's house'. This may have represented a convergence between renal patients' status as leaseholders and their social roles associated with age. As Finlayson argues, and as the following section explores, housing dependency and entitlements to shelter were conceptualised very differently by Yolŋu to the way in which they were understood by Territory Housing.

Urban public housing redistribution in Yolŋu domestic moral economies and the 'visitor problem'

One morning Helen invited Yinin and I to visit her at her one bedroom public housing unit, located in a major suburban public housing complex. I was grateful when she motioned for me to sit beside her on the linoleum-covered floor – I had been uncertain where to sit, or how to make my way inside the front door. Helen had almost no furniture, but I counted ten people inside her tiny unit besides Yinin and I. Some were sitting on the living room floor, sharing a breakfast of rice and minced meat, eaten out of cooking pots, and milky tea sipped communally out of large plastic containers. Others were lying on mattresses, still sleeping. Still others spilled out into the kitchen, sitting on the benches. I visited Helen many times during my fieldwork, and while she and her daughter Bilinydjan, who was caring for her, and Bilinydjan's two teenage children were the usual residents, there were always several visitors.

Helen had been living in Darwin in order to access dialysis treatment for 13 years before I met her. In that period she had experienced a varied housing biography, moving between two hostels and a relative's public housing abode, as well as spending a brief period sleeping rough before securing public housing herself. After Bilinydjan started caring for Helen, they had applied for a transfer to a larger property, but never seemed to be allocated one. Helen and Bilinydjan had first applied for a transfer several years prior, and continued to wait throughout my fieldwork. Their circumstances meant that Bilinydjan's husband couldn't live with her due to Yolŋu protocols of appropriate relations between mothers-in-law and sons-in-law – the one bedroom unit was too small for them to avoid being in the same room or seeing each other enter the bathroom.

Helen felt that she had not been provided with the housing due to her family:

> *I went back to Housing and I put Bilinydjan and the husband one and two kids* (on the application for a larger house) *but they didn't help us. Yeah. Help me like proper housing because I need a family. Instead I have to help myself. And if something's happen like drunken people comes around or throws a rock or stick, you know, I need a family. … I need a family like everybody's having family too. And they still can't help me with that, through the Housing. …What about my carer, I need two bedroom, give me three bedrooms… Because I'm getting weak, skinny one.*

Helen often talked about having family close as a form of security. The complex in which she lived had a local reputation for violence and crime. While it was unclear whether this reputation was entirely deserved, some government agencies forbade their staff from visiting clients there due to safety concerns. Patient buses that transported patients from their homes to dialysis appointments also declined to provide after-hours services to patients living in some public housing complexes due to the risks seen to be present in such locations.

Helen was at once a care-giver and care-receiver and expressed a desire for housing that reflected Yolŋu practices of care. She described a need for a spare bedroom for visiting carers and other relatives, including children she would look after, but who were not recognised in bureaucratic systems as being in her care:

> *I… need 2 or 3 bedrooms because the kids have to stay for holidays, Christmas, but still they can't. I need to stay with family, they visit for a few weeks. People still come to see me. I'm still in a one bedroom house. I want to see my grandkids sitting and talking with me, arguing, making fun of me. I need them. I need to be yelling and screaming to my grandkids, like screaming's love. That's why I'm a bit worried. They* (Territory Housing) *say you have to stay here* (in the present house) *because Bilinydjan's two kids are not in your care.*

Helen's desire to argue with, yell and scream at and be made fun of by her grandchildren recalled the *märi –gutharra* relations discussed in Chapter Three. *Märi –gutharra* relations, between a mother's mother or mother's mother's brother and daughter's child or sister's daughter's child, were described as invoking reciprocal relations of care and as characterised by playfulness and informality. Collective practices of care in which grandparents provided extensive care to young grandchildren, particularly when parents were teenagers or young adults, were common amongst Yolŋu interlocutors but poorly recognised in housing policy as well as eligibility criteria for social security.

The reasons that Helen's visitors gave for their presence in Darwin were diverse, but were often associated with giving and receiving care and frequently reflected the centralisation of government services in the town. One woman was visiting a grandson in jail. Another was a fellow renal patient

who had been sleeping rough. Some young women had come to take children to the Darwin Show (an annual carnival) during the school holidays. The succession of visitors in interlocutors' homes reflected, in part, collective, rotating practices of care discussed in Chapter Three. Although not all visitors described their primary purpose in Darwin as care-giving, visitors with other objectives in the town often also provided care for their hosts and other visitors. Some Yolŋu interlocutors considered the very presence of relatives to be a form of care.

Helen was not always amenable to the presence of visitors in the unit. She often complained about the cramped conditions, and of some visitors failing to meet expectations of reciprocity in contributing to groceries, rent and cleaning chores, while she was also concerned about negative reports from housing inspectors. Feeding a large household was an expensive undertaking and Helen often ran out of money ahead of her fortnightly Disability Support Pension payments and she and the other residents frequently went hungry. She asked me to loan her money for groceries from time to time, and she and Bilinydjan sometimes took out small loans with payday lenders. When she invited me to visit her at dialysis one day, her recorded weight was only 41kg, and a nurse was administering a nutritional supplement to her blood[26]. Helen, however, felt that asking visitors outside of close family to contribute to the household was impinging on their autonomy, explaining, 'I can't ask them, let them think for themselves'. In another conversation, she added, 'how I'm gonna kick them out – look after me still?', evoking interdependencies between kin of shelter and care.

It was not always clear why some of Helen's visitors didn't contribute financially to the household. One visitor, however, was paying much of her income in debts to a payday lender. Some may have been contributing rent to properties elsewhere. The sedentary bias of Northern Territory housing policy made it difficult to make official changes of address with Territory Housing, and doing so could also impact on the tenancies and rents of other residents.

Helen's hospitality was not without limits and she discussed refusing to accommodate relatives who were drinking, in compliance with her tenancy agreement. However, Helen evidently felt an obligation to provide care and shelter to her visitors beyond the expectations of her tenancy agreement, as well as expectations of reciprocity from visitors. Helen's felt obligations, the actions of her visitors and the expectations contained within her tenancy agreement could, however, leave her feeling conflicted. Helen's visitors sometimes brought her gifts of wild honey from north east Arnhem Land and she

[26] Malnutrition among renal patients may represent complications of end stage kidney disease, as well as the social and economic environments of patients (Hoy et al. 2001; Kovesdy 2016).

sometimes described herself as a queen bee, ensconced in her nest while other relatives whirred around her, creating conflicting imperatives, as in the following conversation with Yinin:

> Helen: *I worry when the next lot of family is coming. I don't know. They come and visit Darwin, I always say stay here unless you're drinking, but it's ok for your family to stay...* (I feel) *like a honey bee,* (they go) *in and out. I look after them and they look after me.*
>
> Yinin: *There are too many people, she complains, but as soon as they leave she worries straight away. Lots of people come in, ask for food.*
>
> Helen: *Make me feel loved, cared for.*
>
> Yinin: *that's the connection, kinship… if you see lotta people living in one house that's the way it is, not gonna stop.*

Other interlocutors described frail, elderly relatives in public housing as lacking the strength to manage visitors. Elderly tenants such as Helen were likely to have been highly entangled in interdependent relations of care.

Helen enlisted my help on a few occasions to find second hand furniture to purchase – beds, couches, a TV stand and a set of drawers. While other relatives were concerned that there would be no space for furniture in the unit between all of the bodies inhabiting it, Helen's intention was to reduce the amount of space in which visitors could be accommodated. On my subsequent visits to Helen's unit, invariably, the furniture would end up pushed against the walls or on the nature strip outside.

……

In Yolŋu domestic moral economies, public housing is implicated in the production of social value in people, relationships and family solidarity. Public housing is instrumentalised in practices of mobility, performing domestic labour and sharing shelter and food with kin. The negotiation of care in Helen's household invoked generalised forms of reciprocity and interdependencies amongst kin, of the kind discussed in Chapter Three, encompassing material and non-material forms of sharing and care. Helen was cared for by visitors while looking after their children and providing shelter and sustenance to all. The failure of some of Helen's guests to fulfil her domestic expectations was not described by Helen as grounds for relinquishing her own responsibilities of care, or asking them to leave: extending shelter and hospitality to kin did not compel mutual obligation, or immediate, direct reciprocation. Helen did impose some behavioural constraints on visitors, refusing to accommodate those who were drinkers. However, drinkers may have been turned away on the basis of their likely disruption of other responsibilities and interdependencies of care of care within Helen's household, particularly those concerning young grandchildren, as well as on the basis of drinkers' contravention of Helen's tenancy

agreement. In this section I discuss the interaction of disparate practices and values of care in Northern Territory housing policy and amongst the families of Yolŋu renal patients.

Urban public housing allocation practices within Territory Housing that created differential access to public housing amongst Yolŋu renal patients and their kin could give rise to responsibilities among renal patients to provide shelter to their families. Differential access to public housing among renal patients and their kin could endow renal patients with what Gaynor Macdonald describes as 'allocative power', or the capacity to respond to the needs and demands of kin; and in doing so, elicit respect and authority, and reaffirm kin relationships (Macdonald 2018). Renal patients living in public housing were cast as housing dependent in Northern Territory housing policy. Yet, renal patients residing in public housing could also become housing providers through the distribution of public housing by Territory Housing in ways that endowed them with allocative power and through practices of sharing and redistribution in Yolŋu domestic moral economies.

Disparate values and expectations of care in housing between Territory Housing and Yolŋu families were brought into relief in disputes over the presence of visitors and the conduct of some. Contention over visitors represented tensions between values of self care in Northern Territory housing policy and the social value that Yolŋu derive from caring for one another. This dilemma, which I term the 'visitor problem', could manifest in conflicts between residents and, in Bilinydjan's case, the separation of families. The 'visitor problem' could also play out through internal conflicts and conflicts between tenants and housing officials. Conflicts over norms of dwelling were underscored by a housing official involved in conducting housing inspections who was frustrated by the task of checking where residents and visitors were residing. 'I wish they'd just stay put, it makes it really hard for us', he complained. The mobility of residents could mean that 'all our data is gone'. While urban public housing shortages could give rise to the distribution of housing through particular conceptualisations of housing need, the task of governing scarce public housing could also reinforce a politics of behaviour in residents' homes. The politics of behaviour in the public housing homes of Yolŋu renal patients was also a politics of care.

While the extension of shelter and care by Yolŋu public housing tenants to visiting kin could express familial obligations that worked through an affective register in some cases, the 'visitor problem' did not always represent altruistic gestures on the behalf of public housing tenants. One interlocutor described the response of a relative to housing inspectors concerned about the presence of several visitors at her public housing abode. The relative responded to inspectors, 'all I know is that I don't count people. Because the kinship counts'. In a conversation with Mr Muŋuḻpurr and Wapiriny about

accommodating kin, Wapiriny, despite earlier telling me that he had been 'three or four times kicked out of houses' by Territory Housing due to the presence or behaviour of kin, explained that kin could not be turned away because providing hospitality was a Yolŋu 'tradition'. Mr Muŋul̲purr, who had also experienced eviction due to visitors, added that honouring kinship was the 'foundation' of Yolŋu society. He continued, 'if you burn down a house, all you've got left is the foundation. Without the foundation we're nothing'. As I have noted in previous chapters, for Yolŋu, discharging responsibilities to kin, including by providing shelter, could make one a particular kind of person who takes responsibility for others' needs and could reaffirm kin relations. Housing authorities who saw themselves as helping residents to manage unwanted visitors missed the point that practices of providing shelter are enactments of relatedness, personhood and agency. Denying kinship evidently presented an existential threat which, for some, such as Helen, Wapiriny and Mr Muŋul̲purr, was a more serious proposition than the threat of food insecurity and the threat of eviction and the *longgrass*.

Indigenous practices of sharing are often depicted negatively in policy and popular narratives as a process of Indigenous subjects succumbing to the unrelenting pressures of kinship, as Jon Altman notes in relation to demand sharing practices (Altman 2011). Yet, as Altman proceeds to argue, sharing represents a negotiation of kin relations. My interlocutors illustrate here how practices of sharing habitable space represent an ethic of care, and the exercising of a relational form of agency, based on the strength of one's relationships to significant kin. The relational mode of agency that Yolŋu embody further extends Altman's assertion, opening up a new vantage point on sharing practices which at once nurture and represent the exercise of personal agency. However, Yolŋu who exercise a relational form of agency by accommodating kin could find themselves subject to the 'visitor problem' and housing precarity.

The 'visitor problem' could threaten tenancies and in some cases result in eviction. Those evicted from public housing could be excluded from applying for or residing in public housing for two years, or until any debts owed to Territory Housing were settled. Interlocutors evicted from public housing were likely to seek accommodation in other relatives' public housing, leading to a cascading effect of threatened tenancies. The eviction of a Yolŋu family from public housing following the death of a renal patient mentioned in the previous section resulted in some of his co-resident family moving into the public housing abode of another relative in Darwin. There, they were joined by former members of another evicted household, in what became another crowded house. As being on the public housing wait list was also a criterion for accessing several forms of supported accommodation and other support services, the 'visitor problem' could have broad ramifications for housing security. As Daphne

Habibis and her collaborators have illustrated, attempts to reshape Indigenous peoples' norms of dwelling through social housing may deepen housing insecurity (Habibis et al. 2013). Through a punitive approach to tenant conduct, the governance of housing could marginalise Yolŋu practices of care, and could reinforce housing precarity.

Virtually all interlocutors living in public housing had experienced the 'visitor problem'. Their experiences were either related to me first hand, or by relatives concerned for their welfare. Wapiriny complained that:

> *Once you get a house you've got lots of family. Family will know once you get a house, they're the ones who are gonna kick you out. Unless you get a place in Humpty Doo* (a rural town on the edge of Greater Darwin)*, a long way out, that's good, no one's gonna come… back home there are no problems, family's your enemy here.*

Wapiriny subsequently conceded that in north east Arnhem Land communities, a different set of housing problems existed in accessing properly maintained houses. Another interlocutor, Gutjan, agreed that the 'visitor problem' was not a fixture of north east Arnhem Land communities, although people did visit one another, and was produced by Darwin's 'housing rom (laws, rules, norms), if family wants to stay, only two weeks'. Interlocutors agreed that two weeks was not sufficient time to enact the relational practices that motivated their visits. Wapiriny and Gutjan demonstrate that Territory Housing's approach to visitors could lead to strains on familial relations. The different sociality experienced by renal patients living in Darwin, described in Chapter Two, could be a product of the ways in which lives and care were governed in urban areas.

The 'visitor problem' is extensively documented in studies of Indigenous practices of dwelling from across Australia (for example, Birdsall-Jones & Christensen 2007; Daly & Smith 1999; Habibis et al. 2013; Long, S et al. 2007; Milligan, V et al. 2011). Territory Housing operated an Intensive Support Unit to assist tenants at risk of eviction, which included assistance with 'visitor management'. Staff described the work of 'visitor management' as reminding tenants of their responsibilities as stipulated in tenancy agreements, and sometimes asking visitors to leave on behalf of tenants.

While the 'visitor problem' represented divergent values of care in housing, it was sustained by interdependencies between housing policy objectives of reducing rough sleeping in the presence of public housing shortages and Yolŋu practices of accommodating kin. Yolŋu practices of extending shelter to kin could result in overcrowded dwellings. However, Helen's narrative illustrates how such practices also addressed chronic public housing shortages and the centralisation of government services, providing shelter to some who may have otherwise slept rough.

Official data provide some evidence of how the 'visitor problem' is sustained through interdependencies between housing policy agendas and Indigenous families at a population level. Homelessness amongst Indigenous people in the Northern Territory differs in severity and character to homelessness amongst other populations. Indigenous people comprise 88% of all homeless people in the Northern Territory (Northern Territory Government 2018b). The Australian Bureau of Statistics defines a person as homeless if their living arrangement is in a dwelling that is inadequate (for example, overcrowded); they have no tenure, or their initial tenure is short and not extendable; or their living arrangement does not allow them to have control of, and access to space for social relations. In the Northern Territory, 81% of homeless people live in severely overcrowded dwellings, compared to a range of 16 – 45% of homeless people in other states and territories (Australian Bureau of Statistics 2018). Extremely high rates of homelessness amongst Indigenous Territorians, the vast majority of which manifests in severely overcrowded housing, suggest that the rough sleeping population would be substantially higher in the absence of Indigenous practices of sheltering kin. While some housing officials saw Indigenous visitors to Darwin as exploiting relatives' access to housing, including the housing of renal patients, public housing programs and Indigenous practices of care and redistributing shelter were mutually parasitic.

Interdependencies between housing policy objectives of preventing rough sleeping and the families of Indigenous renal patients in securing accommodation and providing care were further underscored by emergency accommodation measures for renal patients lacking shelter and domestic care. Royal Darwin Hospital has a patient discharge policy of 'no exit to homelessness'. Senior Department of Health officials confirmed that in cases when no accommodation is available to refer patients to, staff at times operationalise the policy by keeping patients at risk of sleeping rough as hospital inpatients. I was relayed second-hand information about similar practices at Alice Springs Hospital, where a blind Indigenous renal patient, who had relocated to Alice Springs for treatment without accompanying relatives, and who was not assessed as eligible for supported accommodation, had been living for two years. The patient's lack of domestic care made unsupported forms of accommodation unsuitable. The practice of accommodating patients lacking shelter in hospitals, while preventing rough sleeping, can place pressure on hospital beds, resulting in periods of 'delayed discharge' or 'bed block' in which all elective surgery is cancelled . At Royal Darwin Hospital, there were at least three prolonged periods of 'delayed discharge' in 2018 (Northern Territory Government 2018a). The accommodation of renal patients without housing or domestic care in hospital beds, at large cost to the state, further illustrated material dimensions of the interdependency between housing policy objectives of preventing rough sleeping and practices of extending shelter and care to kin in Indigenous families.

Hostels and the 'visitor problem' reconfigured

Renal patients excluded from public housing due to long wait lists or eviction often resided in forms of supported accommodation such as hostels, transitional housing, independent living units at nursing homes and women's shelters. Such facilities tended to offer less secure, short term accommodation. These facilities tended to more strictly impose or attempt to enculturate certain modes of dwelling compared to public housing. Some did not allow visitors to reside on their premises while others imposed more strict limits on visitors compared to public housing, configuring the 'visitor problem' in a different way.

Several interlocutors resided at hostels designated for Indigenous visitors to Darwin. These facilities, mostly operated by the Commonwealth-government owned corporation Aboriginal Hostels Limited as well as NGOs, provided board and three meals a day. Aboriginal Hostels Limited was established in 1973 with the objectives of offering temporary accommodation for travelling Indigenous Australians that enabled travellers to avoid the racism seen to exist amongst private accommodation providers; and of preventing homelessness (Ross 2000). Although Aboriginal Hostels Limited did not accept residents with high care needs, and some facilities were unable to accept people requiring wheelchairs, Darwin-based hostels had nevertheless accumulated many long term residents who were often renal patients.

Hostels provided one means of resolving the 'visitor problem'. They accommodated residents through forms of paternalism that removed direct control over paying bills, making provisions for meals and allowing visitors to stay. Indigenous renal patients tended to congregate in hostels with their own countrymen and women, such that different facilities had become associated with different groups. While hostels could be sites of sociality and community, patients' partners, carers and temporary visitors could only stay by making their own bookings and paying for their own board, even if sharing a room with a relative or partner; and hostel tariff rates prevented many from doing so. Residents of Aboriginal Hostels Limited facilities were charged a flat rate of $31 AUD per night, which was below market rates and heavily subsidised, but still left them with little disposable income. Hostel tariffs were unaffordable for those receiving unemployment benefits (Puszka 2019). The likely eligibility of renal patients for the Disability Support Pension or Age Pension, paid at much higher rates (see Chapter Six), provided renal patients with greater access to hostel accommodation compared to their kin. Mr Muŋuḻpurr complained that hostels violated long-standing Yolŋu customs of offering shelter to relatives without expecting direct repayment: 'this hostel got different rom (laws, rules, norms) but

we say no…everything's got money, gotta pay. We saying no. That's our law. That's bin pass on to this generation and now we're sharing to the next generation'. Hostels offered access to accommodation without providing residents with allocative power. Residents often complained about hostels' institutionalising environments, in which they had little control over the food they ate, the times it was served and little disposable income after paying tariffs. The interdependencies of sharing and care integral to Yolŋu domestic moral economies could be difficult to sustain in hostels; and most interlocutors living in hostels described their reasons for doing so as underscored by a lack of alternative options.

The low incomes of unemployment benefit recipients precipitate a degree of reliance of the Aboriginal Hostels Limited business model on renal patients. Aboriginal Hostels Limited operates one small facility designated for renal patients and three other multipurpose hostels in Darwin. In all three multipurpose facilities, upwards of 75% of residents are undertaking medical-related travel, including high numbers of renal patients (Aboriginal Hostels Limited 2019). Housing officials and service providers told me that there were further reasons for Aboriginal Hostels Limited to attract renal patients, echoing the conceptualisations of legitimate housing dependency that characterised renal patients' greater access to public housing. A Territory Housing bureaucrat and other housing support workers commented that hostel managers liked to attract renal patients because they tended to have 'quiet' lifestyles, often did not consume alcohol, and were less likely to 'cause trouble'. Other local service providers suggested that the sedentary requirements of renal patients' treatment were likely to make them a reliable source of revenue. Like these interlocutors, Aboriginal Hostels Limited itself failed to recognise the interdependent relations between the corporation and renal patients, subjecting them to paternalistic measures that treated them as dependents and prevented hostels from being experienced as sites of care.

Private rental: another means to realising interdependent relations of care?

A few interlocutors attempted to escape the politics of care in urban social housing and hostels by renting properties through the Darwin private rental market. Although private rental properties were largely outside of their financial means, some cheaper properties that were managed directly by owners rather than real estate agents could be found in a local informal economy. Owners offering an array of dwellings, including granny flats and demountables (portable dwellings resembling shipping

containers) as well as apartments and houses encountered potential tenants through non-commercial websites and personal contacts. In the informal private rental market, owners often did not require applicants to complete forms and appeared to rarely subject them to credit history checks.

Two interlocutors asked me to assist them to find an apartment to rent. Both hoped to share a private apartment with relatives and visitors. Mr Muŋuḻpurr had no close relatives living with him in Darwin for much of my fieldwork, in part a product of his inability to pay for his children to stay at the hostel at which he resided. He had plans to secure a private rental property close to the city with sufficient rooms for his wife, teenaged daughter, two adult sons and temporary visitors to stay. Rent would be rendered affordable through the pooling of familial income. While some landlords seemed sympathetic to Mr Muŋuḻpurr's circumstances, allowing him to pay bond over an extended timeframe if the tenancy went ahead, others seemed reluctant to countenance him as a potential tenant. In one exchange, the landlord's underlying racism was made clear:

> SP: *Hi, I'm ringing about a granny flat you've got advertised in Alawa on Gumtree.*
>
> Landlord: *Oh yeah, where are you from?*
>
> SP: *Actually it's for my friend, he's sitting here with me.*
>
> Landlord: *Well where is he from?*
>
> SP: *Well he's living here in Darwin, but I guess he's from Arnhem Land.*
>
> Landlord: *What, is he Indigenous?*
>
> SP: *Yeah.*
>
> Landlord: *Oh ok.*
>
> SP: *So would we be able to view the property this weekend?*
>
> Landlord: *I'm busy.*
>
> SP: *Well how about Tuesday? Tuesday night after work?*
>
> Landlord: *Yeah ok call me later.* (Hangs up)

Following this exchange, Mr Muŋuḻpurr became uninterested in pursuing the property.

In the many enquiries about properties that I assisted interlocutors with, they almost always made an assessment of property owners afterwards, often commenting 'I had a good feeling about her' or 'I didn't have a good feeling about him'. Interlocutors seemed much more concerned with the character

of potential landlords than with the appearance of dwellings. They resented property owners' probing of their personal lives and finances, appearing to impute a lack of trust on the behalf of owners. Interlocutors' attempts to rent properties through the private market were rarely successful. While private rental properties represented housing independence and self care in Northern Territory housing policy, I argue that Yolŋu renal patients who sought private rental properties were attempting to realise Yolŋu values and practices of care through the private market. Interlocutors such as Mr Muŋul̲purr may have also been attempting to encompass potential landlords in relations of respect and care.

Scholars of dwelling in the social sciences have argued that housing and the way it is governed shape care practices (Alexander et al. 2018; Flint 2004; Power & Mee 2019). Bringing together two strands of literature on the housing of Australian Indigenous peoples, I have illustrated in this chapter the capacity for practices of care to also shape the governance of social housing. Northern Territory housing policy emerges from international neoliberal currents in the governance of housing and the colonial history of the Northern Territory. However, I have demonstrated how Yolŋu practices of extending accommodation to carers and visitors address chronic social housing shortages and may impact on state attempts to relinquish responsibility for housing the vulnerable through disinvestment in social housing. The interaction between Yolŋu care practices and the values of care in Northern Territory housing policy associated with caring for oneself and a nuclear family give rise to a politics of behaviour that leads to the perpetuation of housing insecurity by the state. By foregrounding agentive dimensions of caregiving, social obligation and social indebtedness, and their strategisation in response to housing insecurity, I have illustrated how social housing tenants' care practices and the governance of housing shape one another.

It has often been asserted that neoliberal governance institutionalises precarity and crisis (Hage 2014). I have described here how the interplay of neoliberal, paternalistic and colonial dimensions of Northern Territory housing policy produce categories of legitimate and illegitimate dependency in social housing, creating new forms of inequality and marginalisation among the vulnerable. I have illustrated how neoliberal housing policy not only institutionalises precarity, but also interdependency within families and between social housing tenants and the state.

Conclusions

In this chapter I have continued to explore values and practices of care in Yolŋu domestic moral economies, examining how housing is implicated in social and economic relations of care. I have argued that housing is integral to Yolŋu relations of domestic care, as a locus of care practices and as a resource encompassed within reciprocities and interdependencies among kin. Sheltering kin who might otherwise be consigned to the *longgrass* was considered to be integral to the performance and maintenance of kin relations, and represented an enactment of a relational mode of agency.

In this chapter I have also continued to explore relationships between Yolŋu domestic moral economies and the state, through urban social housing. While I showed that health professionals provide care to renal patients through desires and objectives of fostering patient empowerment and reducing patient dependency in Chapter Four, in this chapter I have shown that public housing was allocated to renal patients through conceptualisations of legitimate housing dependency. Through the concept of legitimate dependency, renal patients' housing needs could acquire greater legibility to Territory Housing than those of their kin. The articulation of categories of legitimate and illegitimate dependency with Yolŋu domestic moral economies, however, could transform renal patients cast as legitimately dependent on the state into providers of shelter for others.

As with the values of care expressed by health professionals in the previous chapter, public housing tenancies were governed through an interplay of values of self care and paternalism. Such values came into contention with the values and practices of care in Yolŋu domestic moral economies, constituted through interdependent relations and generalised forms of reciprocity among kin. While social housing was governed as a resource of hygiene and sanitation and for enculturating sobriety within nuclear families, residents such as Helen instrumentalised public housing as part of the materialities of extended kinship, responsibilities to others and interdependencies of care. While Territory Housing imagined public housing as a site of sedentarisation, public housing was often a resource for mobility for carers and other visitors. While Territory Housing staff considered themselves to be providers of benevolent welfare, values of self care and paternalism embodied both neoliberal and neo-colonial values of care, representing historic continuities in attempts to shape Indigenous norms of dwelling.

Extreme public housing shortages, values of self care and paternalism and categories of legitimate and illegitimate housing dependency could play out in Yolŋu domestic moral economies through a

particular politics of care. Yolŋu renal patients' practices of extending shelter to carers and other kin who might otherwise find themselves sleeping rough could address a lack of social housing and affordable accommodation, but could also threaten their tenancies and in some cases result in eviction. This politics of care, which I have termed 'the visitor problem', was not a feature of remote Indigenous communities, in which social housing is often the only form of housing available to Indigenous residents and in which extreme social housing shortages also persist. The 'visitor problem' was produced by the governance of urban public housing and contending values and practices of care. Through the 'visitor problem', contention over values and practices of dwelling could obscure distributional questions about the adequacy of public housing stock.

Through the 'visitor problem', Yolŋu domestic moral economies are mobilised yet marginalised by state policy agendas in unacknowledged ways. Renal patients' visitors and co-residents, as providers of domestic care, could become implicated in healthcare, as the previous chapter argued. I have argued in this chapter that renal patients themselves could also become implicated in housing policy agendas, as providers of shelter to carers and other kin who may otherwise sleep rough. While Yolŋu patients were considered to be dependent on welfare in healthcare and housing policy, I have argued in this chapter that through housing policy objectives of preventing rough sleeping, relations between Yolŋu and the state as well as relations within Yolŋu families are characterised by forms of asymmetric interdependency. The accommodation of many renal patients in hostels that rely on them for revenue, yet provide accommodation in paternalistic ways that strictly limit visitors, further illustrates the unacknowledged interdependencies between renal patients and state housing policy agendas. The 'visitor problem' institutionalises housing precarity and also housing interdependency, among social housing tenants, their families and the state. As the following chapter will explore, through social security policy, disparate values and practices of care in the interdependent relationship between Yolŋu families and the state could in some cases strain relations among kin. Pressures placed on interdependent relations within Yolŋu families could exacerbate the social suffering of renal patients and could also have consequences for the realisation of state policy agendas.

Chapter Six
Compromised care: Sharing and subsistence in domestic moral economies

Annie was playing basketball with her sisters and cousins in her home town of Milingimbi when she started to feel weak and tired. After the game she went to the local health centre, where following some tests she was told she had end stage kidney disease and would need to move to Darwin for dialysis treatment, immediately and permanently. She was 38 years old.

I first met Annie when I was visiting Helen, her aunt. Annie had relocated to Darwin and commenced dialysis around one year prior. She had come to visit Helen and to have a shower and a meal. One of Annie's older relatives who was also present at Helen's unit asked her for some money, but she said she had none. Another relative explained that Annie was receiving Newstart Allowance unemployment benefits and was subjected to job search requirements while she waited for her Disability Support Pension application to be assessed. A third relative suggested that Annie may have had her Newstart Allowance payments suspended due to failing to comply with the conditions. Annie explained that she had been waiting on the outcome of her pension application for over 8 months. It became evident that her lack of a fixed address and mobile phone, her lack of personal ID and her inability to pay for a new copy of her birth certificate had contributed to delays. In that period, the subsidised accommodation provided by the Northern Territory Department of Health to new patients had run out, and Annie could not afford to continue staying at the Aboriginal Hostels Limited facility she had been living in, where she had been provided with food as well as accommodation[27].

[27] Renal patients relocating to Darwin for dialysis were provided with two to eight weeks of subsidised accommodation through the Patient Assistance and Travel Scheme. They were usually placed in Aboriginal Hostels Limited facilities, where the subsidy covered all costs. After the subsidy was exhausted, patients were required to make their own accommodation arrangements.

Annie sometimes stayed with her mother's ex-husband, an elderly man also undertaking dialysis in Darwin, in his public housing abode, along with his family. The elderly man and his wife had raised Annie after her birth mother passed away when she was a toddler. However, other residents in the two bedroom unit at times complained that Annie didn't contribute enough towards rent or groceries. Living in the unit entailed living with men with whom she had avoidance relations, which brought her discomfort and stress. Annie was at times subject to violence from another relative living in the house. The circumstances of housing in Darwin could mean that for some, such as Annie, the living spaces of relatives were not experienced as places of care.

Social workers at the hospital tried to help Annie, applying for a social security crisis payment to enable her to stay elsewhere for a spell, but the promise of temporary relief proved elusive. Because the violence Annie was subjected to did not take place inside the house, she was ineligible. On at least two occasions, social workers secured temporary accommodation for Annie at a women's shelter, but the two week time limit for crisis accommodation saw her return to the troubled unit after each stay.

Annie sometimes slept rough when relations in the unit became intolerable. She often appeared exhausted and complained, 'Looking for a place, sleeping in the longgrass, staying with family, I can't sleep, I can't rest'. When sleeping rough, Annie was sometimes subject to police surveillance, and she sometimes missed her dialysis treatment when the patient bus couldn't find her. On a number of occasions, when she became sick from the build up of fluids and toxins in her body, she was rushed to the emergency department and admitted to hospital.

I offered to help Annie apply for a new birth certificate for her Disability Support Pension application, and once her Pension was approved, to assist her to move back into a hostel, according to her wishes. I made plans to take her the next morning to the Registry of Births, Deaths and Marriages, along with Helen, another older female relative who was staying at Helen's house, and Yinin, who was also related to Annie. However, the next morning, Annie could not be located. Helen explained that Annie had taken off earlier, fearing becoming entangled in another bureaucratic encounter that she did not understand, and over which she had little control. Annie later admitted to me, 'it's really hard for me to ask (for help), I feel hurt'. She added, 'it's a very hard way of life here in Darwin. There's no place to stay'. Despite her circumstances, Annie was reluctant to ask strangers not encompassed in interdependent relations of care for help.

……

Annie's predicament evinced multiple public policy failures, compounded by strains on the interdependencies of kinship. Annie embodied the unintended consequences of conflicting health, housing and social security policy imperatives. Without a Disability Support Pension, she could not afford to continue staying at an Aboriginal Hostels Limited facility and had limited ability to make financial contributions to her mother's ex-husband's household. Without a stable fixed address, correspondence regarding her Pension application was not received and dialysis treatment was difficult to sustain. It was the lack of care in her mother's ex-husband's unit, however, that finally led Annie to sleep rough. Although her mother's ex-husband attempted to assist her, advising her about dialysis and the dangers that missed treatment presented, his frailty limited his ability to protect Annie from others in the house. Annie would not have had such a limited pool of kin from whom to seek help had she been receiving treatment in Milingimbi, and her displacement to Darwin underscored her inadequate subsistence and care.

In this chapter I continue to investigate material dimensions of care. I bring analytic attention to Yolŋu care practices associated with the pursuit of subsistence for oneself and one's kin, of sharing money and food and of hunting and gathering. I consider the interaction of such care practices with social security policy. I further explore how welfare resources may be assimilated into Yolŋu domestic moral economies and how the care of the state for Yolŋu renal patients and their kin exploits social roles and responsibilities in Yolŋu families. I show how the interaction between the care of the state and Yolŋu domestic moral economies could, in some circumstances, leave a renal patient like Annie without care or adequate subsistence.

Anthropologists of Australian Indigenous economies have tended to emphasise conflicting imperatives between market capitalism and its accompanying redistributional systems of social security; and customary economies. A range of scholars have described the conflicts and tensions between customary economies that place value in kinship and social relationships, and deploy practices of sharing and reciprocity; and the valorisation of accumulation and material wealth in narratives of modernity, development and capitalism (Austin-Broos 2009; Folds 2001; Sutton 2009). However, as Jon Altman notes, state welfare may be assimilated into Indigenous economies, producing hybrid economic forms characterised by the integration of market, state and customary economic resources and transactions (Altman 2001, 2007). Nevertheless, the integration of disparate values, practices and resources in hybrid Indigenous economies is unlikely to be a seamless process free of conflict; and I draw on Altman's analysis in this chapter whilst acknowledging that hybrid economies may contain internal tensions and conflicts.

Altman's model (2001, 2007) emphasises hybrid forms of production in remote Indigenous communities. The concept of 'moral economy' similarly expresses economic relations and practices that can exist within or beside market economies, which are underpinned by values and imperatives beyond individual self-interest and profit maximisation (Arnold, P 2001; Owen 2009; Palomera & Vetta 2016). However, the 'moral economy' concept encompasses relations of social reproduction as well as production, and foregrounds the relationships, values and social practices integral to the pursuit of the basic needs of life (Arnold, P 2001; Chattoo & Ahmad 2008), in contrast to the structuralist approach of Altman's model. In this chapter I therefore build on Altman's analysis to explore the integration of social security and labour market-derived income with hunted and gathered resources in Yolŋu domestic moral economies and the impact of urban displacement.

In this chapter I argue that Australian social security, distributed to recipients through intertwined values of economic self sufficiency and paternalism, is assimilated into Yolŋu domestic moral economies through relations of interdependency among kin and practices of generalised reciprocity, or sharing. I argue that social security that offers inadequate subsistence to recipients is parasitic on sharing and hunting and gathering practices among Yolŋu families. Through practices of sharing and hunting and gathering, some of my Yolŋu interlocutors supplemented social security incomes, furthering social security policy objectives of providing subsistence and promoting food security while also subverting other social security policy agendas that attempted to alter Indigenous norms of provisioning. However, the way in which renal patients' lives were governed in Darwin could curtail Yolŋu practices of hunting, gathering and sharing, straining the social fabric of Yolŋu domestic moral economies and subjecting some patients to absences of care and significant bodily, social and economic precarity.

I commence with a brief examination of how Australian social security policy is enacted through values of self sufficiency and paternalism and through categories of legitimate and illegitimate dependency. I consider how policy agendas of curtailing assistance to people deemed illegitimately dependent on the state have been applied to Indigenous people historically. I go on to consider how social security is assimilated into domestic moral economies in the families of Yolŋu renal patients, including through categories of legitimate and illegitimate dependency. I then consider how in some circumstances, the urban displacement of renal patients may compromise hunting, gathering and sharing practices and threaten subsistence and relations of care.

Legitimate and illegitimate dependency in Australian social security policy

'If you have a go in this country, you will get a go', Australian Prime Minister Scott Morrison declared, after taking on the nation's leadership (2018). Through a phrase that was to become a mantra in public speeches and press conferences, Morrison responded to a national campaign by welfare agencies, unions and business groups to increase unemployment benefits (known at the time of my fieldwork as the Newstart Allowance, and subsequently as the Jobseeker Payment), which were paid at rates well below the poverty line and had not increased in real terms for 25 years (ACOSS 2019; UNSW and ACOSS 2018). Newstart Allowance recipients were positioned by Morrison as people who were capable of obtaining employment in the formal economy but had declined to 'have a go'. Receiving unemployment benefits was positioned in Australian social security policy as a choice and as a moral failing of the unemployed (Morris & Wilson 2014). Recipients were cast by Morrison as illegitimately dependent on social security and low rates of payment were justified as a deterrent.

Newstart Allowance recipients, understood as dependent on the state, were cast in social security policy as illegitimately dependent on the state and as requiring personal reform that would shape them into responsible, self sufficient citizens. In addition to the low rates of payment, recipients were subjected to extensive conditionality as a further deterrent to unemployment. They were required to undertake job search and employment readiness activities (Davidson & Whiteford 2012: 35-38)[28]. In the Northern Territory, they were also subject to compulsory income management, through which 50% of payments were quarantined for expenditure on 'priority items' and could not be spent on alcohol, cigarettes, pornography, gambling or accessed in cash (Bray et al. 2015). As noted in the Introduction, income management was initially introduced in response to allegations of child sexual abuse and social dysfunction in remote Northern Territory Indigenous communities and was subsequently applied throughout the Northern Territory (Bray et al. 2015). It represented an attempt to curtail Indigenous practices of sharing money with kin, through a particular construction of recipients' responsibilities for their own subsistence and the subsistence of a nuclear family (Altman 2011; Klein 2016; Puszka et al. 2013).

Despite Morrison's characterisation of social security policy as a means of disciplining the unemployed, Australian social security policy also aims to provide beneficiaries with a basic

[28] Mutual obligation requirements of the Newstart Allowance are structured in different ways in remote areas through the Community Development Program, and until recently were more onerous than in non-remote areas (Fowkes 2019).

subsistence safety-net. An Australian Government submission to a recent parliamentary inquiry into the adequacy of Newstart Allowance stated:

> *The primary purpose of the income support system is to ensure a minimum standard of living for those unable to support themselves through work, savings or other means* (Australian Government Department of Social Services 2019: 8)

Furthermore, another recent parliamentary inquiry into food prices and food security in remote Indigenous communities was initiated by the Australian Government (House of Representatives Standing Committee on Indigenous Affairs 2020). These developments demonstrate that the basic subsistence of vulnerable populations remains a policy concern that competes with, and is subsumed by, neoliberal objectives of disciplining the unemployed.

The values embodied by Australian social security policy can be understood in a similar way to Soss, Fording and Schram's (2011) characterisation of social security in the United States, intertwining apparently divergent neoliberal and paternalistic values of care. Neoliberal values of economic self sufficiency and imperatives of minimising state intervention in labour markets produce low rates of payment that are substantially means-tested. Concurrently, paternalistic objectives of shaping recipients' conduct in order to produce responsible citizens are reflected in the presence of payments at all and in the extensive conditionality applied to them. As I have argued of healthcare and social housing in previous chapters, paradoxically, paternalistic measures are deployed in social security policy in attempts to compel greater self sufficiency amongst recipients cast as dependent on the state.

In contrast to the Newstart Allowance, the Disability Support Pension, Age Pension and Carer Payment were premised on reduced capacity to work and invoked a different blend of neoliberal and paternalistic policy imperatives. Although these payments also afforded a level of income that fell below the poverty line (UNSW and ACOSS2018), they were paid at substantially higher rates than the Newstart Allowance (Table 2), and reflects a policy objective of providing a subsistence safety-net to a greater degree. The higher rates of the Disability Support Pension, Age Pension and Carer Payment were argued to reflect the costs of giving and receiving care, for example, the need for transport by taxi amongst people with physical impairments who are unable to access public transport (Soldatic 2018). However, these payments were indexed to male full time average weekly earnings, while the Newstart Allowance was tied to the slower-paced Consumer Price Index; and the Newstart Allowance had been steadily declining relative to other payments for some time (Morris & Wilson 2014). I argue

that through the Disability Support Pension, Age Pension and Carer Payment, tied to changes in a living wage, the state recognised more expansive responsibilities of care towards those who were defined as occupying a habitus outside of the labour market and constructed as legitimately dependent. The responsibilities of those categorised as legitimately dependent were constructed in a far more minimal way. The Disability Support Pension, Age Pension and Carer Payment also had fewer conditionality requirements and were not subject to income management (Soldatic & Fitts 2019). Eligibility criteria for the Disability Support Pension have been tightened over recent decades and are now premised on inability to undertake paid work in the formal economy rather than the presence of illness or disability (Li et al. 2019), representing shifting conceptualisations of legitimate dependency.

Table 2 Social security benefits per fortnight ($AUD) as at April 2019

Newstart Allowance[a]	Disability Support Pension[b]	Age Pension[c]	Carer Payment[d]
$546	$834	$834	$834

[a]Fortnightly rate for a single person with no dependent children
[b]Maximum basic fortnightly rate for a single person aged 21 or over, excluding the Pension Supplement and Energy Supplement
[c]Maximum basic fortnightly rate for a single person or a couple apart due to ill health, excluding the Pension Supplement and Energy Supplement
[d]Maximum basic fortnightly rate for a single person, excluding the Pension Supplement and Energy Supplement

Source: Centrelink (2019)

Many Yolŋu with end stage kidney disease were recipients of the Disability Support Pension or Age Pension. Most of my interlocutors were not undertaking any kind of paid work in the formal economy and it was difficult to figure them as participants in the labour market. Many described themselves as too unwell to work. Annie, for example, described her former position as a basketball umpire, as well as a coach and player, as 'finished' due to her illness, despite the availability of such roles in Darwin. Complications of end stage kidney disease can include physical impairments, frailty and fatigue (Klang & Clyne 1997; Tsutsui et al. 2009), while the demands of thrice-weekly treatments and the large volume of medical appointments beyond dialysis that patients attend further impeded their ability to take up formal employment. A few interlocutors, however, were in part-time or casual work that drew on their knowledge and authority as elders and leaders, in Indigenous organisations and in various research projects. Some were also paid members of various governance or advisory boards constituted by government authorities and Indigenous organisations. Some patients' carers and other co-resident kin were also undertaking work in the formal economy, although many were not. Many carers and co-resident kin of renal patients were receiving Newstart Allowance. Analysis of census

data shows that Indigenous people who migrate from remote to urban areas have lower rates of employment compared to those who remain in remote communities (Biddle 2010)[29]. Yolŋu with end stage kidney disease tended to have greater ability to mobilise resources through social security and also in some cases in the formal economy than their carers and other kin in Darwin. As with social housing, the mediation of social security payments through categories of legitimate or illegitimate dependency, bestowing different rates and conditions of payment on recipients, could create material inequalities among Yolŋu.

Historic exclusion of Indigenous people in the Northern Territory from the Australian welfare state

While contemporary social security policy in Australia is animated by a particular blend of neoliberal and paternalistic imperatives that constrain the distribution of welfare, the proposition that Indigenous people in the Northern Territory ever received the full benefits of the Australian welfare state remains questionable. Historically, welfare provided to Indigenous people in Australia has been characterised by measures that create material dependency on the Australian state, and concurrent measures that attempt to prevent the same dependency, often producing exclusion from the full benefits of welfare programs. Exclusion from welfare programs has historically been tied to the uncertain legal status of Indigenous people within the Australian state, and citizenship rights were not extended to Indigenous people until the 1960s in the Northern Territory (Cunneen & Libesman 1995; Peterson 1998).

In periods of initial contact and early settlement, which took place at different times in different regions of the Northern Territory, welfare was often provided to Indigenous people as a benevolent measure to assuage economic dispossession and original displacement from customary economies. Colonial administrators, police and missionaries often distributed rations to local groups as a form of benevolent welfare or as a peace-making gesture (Rowse 1998). Although Yolŋu were not generally dispossessed of their land as many other Indigenous people were, as noted in the Introduction, they were eventually also subject to colonial practices of distributing rations. The practice of paying Indigenous workers in rations prior to wage equality in 1967, particularly within the pastoral industry across northern Australia, has also been well documented (Jebb 2002; McGrath 1987; Rowse 1998). Although subsidies were provided to pastoral companies and missions employing Indigenous workers,

[29] However, rates of employment in remote Indigenous communities are likely to have declined since the disbanding of the Community Development and Employment Program in 2015 (Jordan 2016).

they were rarely received by workers themselves (Tatz 2001). The result was effective exclusion from the cash economy (Altman & Sanders 1995; Rowse 1998).

State practices of placing restrictions on social security distributed to Indigenous people became more systematised in the early assimilation period. The assimilation framework, from around the 1950s to 1970s, coincided with the emergence of the post-war welfare state and aimed to foster racial equality through the cultural absorption of Indigenous people into settler society (Cunneen & Libesman 1995; Rowse 1998). Objectives of racial equality did not imply equal treatment and by the 1950s Indigenous people were only eligible for child endowment, unemployment and sickness payments (Tatz 2001). When all social security payments were extended to Indigenous people in 1960, the qualification of conforming with 'non-nomadic' norms remained (Altman & Sanders 1995; Cass, B 2004). Assimilation was implemented with the view that limited contact with the cash economy was necessary to ensure Indigenous people did not become enculturated to the excesses of capitalism. In the Northern Territory, social security payments were generally not paid directly to beneficiaries and were administered by third parties such as state or church authorities, who often distributed them as rations in-kind, rather than as cash payments (Altman & Sanders 1995). In practice, missions often diverted a proportion of payments towards their general expenses (Tatz 2001). A P Elkin (1951), the architect of assimilation, argued that Indigenous people should be induced to give up Indigenous ways of life gradually through the introduction of small benefits, in order to avoid dependency. The transition to direct social security payments began in the 1960s but was not completed until the 1980s in some instances, particularly for Indigenous people in remote areas (Altman & Sanders 1995; Cass, B 2004). Structural barriers to accessing financial services and the practice of stores continuing to administer Indigenous people's social security payments in remote areas continue to be documented (Marks 2018; Westbury 1999).

The contemporary administration of social security, through ongoing concern about recipients cast as economically dependent, has deep historic roots for Indigenous Australians in the Northern Territory. The category of legitimate dependency in contemporary policy recalls historic paternalism administered to Indigenous beneficiaries designated as unproductive in the capitalist economy. Attempts to shape recipients' conduct, which continue to be administered through a racialised lens to some extent, through income management and different conditionality requirements of the Newstart Allowance in remote areas, also represent historic continuities in the administration of social security.

Yolŋu domestic moral economies and the pursuit of subsistence

In this section I consider how social security articulates with the pursuit of subsistence through hunter-gatherer production in Yolŋu domestic moral economies. I explore how Australian social security policy, which through the Disability Support Pension and Age Pension tends to cast Yolŋu renal patients as legitimately dependent, interacts with the relations and practices of care in Yolŋu families. I show that in Yolŋu domestic moral economies, the pursuit of subsistence mobilises interdependent relations between kin and between Yolŋu and their country.

Subsistence through hunter-gatherer production of foods and medicines

Annie at times described herself as 'starving for white clay (*gapaṉ*)', which she and other interlocutors said reduced blood sugar levels, brought them 'relief' and made renal patients 'feel good' when consumed. White clay is also used by Yolŋu to adorn their bodies with particular designs during ceremonies. Annie enlisted my help on occasion to chip some away from cliffs at Nightcliff Beach. Shellfish, especially *buny'bu* (longbum), and *laitjin* (mangrove worms), were also said to have medicinal properties particularly pertinent to the needs of renal patients: cleansing the body, reducing blood pressure and blood sugar, and containing rich reserves of minerals. Helen explained that 'bush food makes sick people healthy, awake… *l̲aymaram* (brings relief)'. Eating shellfish with their juices elicited memories of other times and places, enabling her to '…. go back like before instead of sitting around, get food from shop, you get really, really, really sick… takes you back to older days, when you were still young, back to normal'. Bu*l̲*anydjan described being sustained by shellfish, telling me, 'just one or two are enough to keep me going'. Yolŋu conceptualisations of health were described in Chapter Two as emphasising experiential dimensions of wellbeing. Medicinal foods and substances of the Yolŋu pharmacopoeia such as *gapaṉ, buny'bu* and *laitjin* elicited desirable physical states, feelings, tastes and memories.

Hunted and gathered resources were valorised by Yolŋu, not only for their capacity to elicit desirable experiences and states, but also for the forms of value that they enacted in a Yolŋu ethics of care. Yolŋu associate collecting shellfish and mangrove worms with the labour of young to middle aged women, and men and elderly and unwell women relied on relatives to obtain such resources. Hunting and gathering generally appeared to be forms of labour associated with younger and middle aged people, and invoked particular practices of sharing among kin. Interlocutors described protocols that specify the ways in which hunted foods should be shared, particularly for larger game associated with

men's productive labour, amongst the successful hunter, the captain of the boat (for fish and other water-bound food sources), others involved and the hunter's close kin; while shellfish collected by women appeared to be shared amongst those present, including men who waited besides fires while women worked inside thickets of mangroves, but quantities could also be set aside for absent others. The ethnographic record is consistent with these observations and descriptions (eg: Schwarz 2017; Thomson 1949). Store-purchased foods favoured by interlocutors such as hamburgers, hot chips and take-away curries were also sometimes shared, but appeared to be more easily monopolised and were not subject to similar protocols. When planning shared meals cooked over a fire with groups of interlocutors, they often requested I purchase whole fish, and not individual fillets. Each roasted fish was distributed to a small group of close relatives. Fish were either consumed by small family groups communally, or were consecutively passed from family heads and older relatives to young children and lastly to teenagers and young adults, with each consuming their share in turn.

Productivity, vitality and sociality were intertwined in acquiring and sharing hunted and gathered resources (cf Graeber 2001; Schwarz 2017). On several occasions in discussions with me, interlocutors noted their capacity to supplement inadequate social security incomes with hunted and gathered foods in north east Arnhem Land. Several expressed similar sentiments to Helen, who commented that hunted and gathered resources provided 'easy food', particularly when one ran out of money. Ethnographic and public health studies show that hunted and gathered food sources are a significant contributor to the diets of Indigenous people residing in remote Northern Territory communities (Altman 1987; Ferguson, M et al. 2017).

Caregiving in Yolŋu families may be understood as integrating practices of hunting and gathering, customary medicine, biomedicine, domestic labour and welfare resources such as social housing and social security. Because social security rates are inadequate, the state policy agenda of alleviating hunger - evident for example in a government-initiated inquiry into food security (House of Representatives Standing Committee on Indigenous Affairs 2020) - cannot be realised without hunting and gathering. Yet the state compromises hunter-gatherer production. This is a form of subsistence more accessible to the residents of homelands, who generally have rights to hunt and gather on the country on which they reside. As Jon Altman has repeatedly argued, hunter-gatherer production has become increasingly threatened by the withdrawal of government financial support for homelands and the diversion of the labour of Newstart Allowance recipients to compulsory employment readiness programs (Altman 2009b, 2018a, 2018b)

Subsistence through differential rates of social security and practices of sharing

The inadequate subsistence afforded by the Newstart Allowance could also precipitate the material reliance of Newstart recipients on kin receiving higher rates of payment, such as renal patients. Many Yolŋu interlocutors who were caring for renal patients in their families were receiving the Newstart Allowance as Yolŋu practices of care were poorly recognised in Carer Payment eligibility requirements. Requirements of a single, sedentary, long term carer contrasted with Yolŋu collective practices of care through rotating carers described in previous chapters. Ŋarritj, Bu̲la̲nydjan's daughter's son and carer who we encountered in Chapter Three, was not receiving the Carer Payment, which was paid only to one of Bu̲la̲nydjan's carers. Dimensions of care work beyond physical labour, such as keeping those who were lonely or isolated company were discussed at length by Kerin Coulehan (1995) in her ethnography of Yolŋu women living in Darwin. Although my interlocutors told me that keeping renal patients company could prevent them from taking up drinking or missing or ceasing treatment, and could nurture *märr* and agency, such practices were not addressed in Carer Payment eligibility criteria that emphasised care recipients' functional mobility and need for assistance with physical tasks. The care provided by buddies in self care dialysis regimes, considered to produce patient independence in health professionals' narratives discussed in Chapter Four, also did not always meet eligibility criteria for the Carer Payment. Through social security, the state poorly recognises Yolŋu care practices when they diverge from Western norms of care; and through the Newstart Allowance, attempts to divert the labour of carers to the formal economy.

The likely eligibility of renal patients for the Disability Support Pension or Age Pension, paid at higher rates and subject to less conditionality, and the ineligibility of many carers for the Carer Payment, could produce income inequality in Yolŋu families. The capacity of some renal patients to earn income in the formal economy through their knowledge and social status as elders and leaders could further widen different rates of income among kin. Income inequality could subject renal patients to the material claims of their carers and other kin. Punitive measures could also precipitate the reliance of Newstart recipients on renal patients' incomes and willingness to share in order to guarantee their subsistence. Claims on one renal patient's Disability Support Pension were invoked when one of her visitors, a young man perhaps in his early 20s, had his Newstart Allowance suspended. The young man had been breached after failing to attend a mandatory appointment at Centrelink while he had emergency surgery for the removal of his appendix, for which he had been medically evacuated to Darwin. After he was discharged from hospital, the young man relied on my interlocutor, who was receiving the Disability Support Pension, for sustenance and shelter until his payments were restored. Although Centrelink staff eventually reversed the breach, this required approximately four hours of

queuing and appointments and could not take place until he was well enough to attend a Centrelink office. The impact of punitive Newstart Allowance measures on the families of Indigenous Newstart Allowance recipients have also been noted elsewhere (eg: Jordan 2016; Kral 2017). As I have shown in previous chapters, in Yolŋu domestic moral economies, legitimate material dependency is constituted beyond the dependency of children and the invalid elderly on their carers and guardians, but encapsulated within broader interdependencies.

Yolŋu also frequently made material requests of kin who were in receipt of lower rates of social security such as the Newstart Allowance. While Newstart Allowance recipients were subject to income management, impediments to sharing managed income with kin appeared to be frequently subverted through the sharing of one's income management card and PIN, although this practice left card holders with less control over the amount of money shared than with the sharing of cash. However, those in receipt of more generous payments as well as income earned through the formal economy appeared to be considered to have greater obligations to share with their families. Yolŋu expectations of sharing expressed value in material equality and the subsistence of all. One woman who was in receipt of the Disability Support Pension, although not a renal patient, was accused by several co-residents of failing to make adequate financial contributions to her household on the basis of her higher rate of payments. The woman in question, however, had accrued debts to a rent-to-own retailer of electronic goods for mobile devices she had purchased for relatives and had little disposable income after servicing her debts. Her income, enabling her to obtain credit, had already been committed to kin. The responsibilities of Disability Support Pension and Age Pension recipients could be structured very differently in Yolŋu domestic moral economies to the way they were conceptualised in social security policy.

Contending conceptualisations of legitimate dependency in Yolŋu domestic moral economies and social security policy could work to reinforce intergenerational interdependencies and generalised forms of reciprocity within families in some circumstances. As in the case of social housing, renal patients, cast as vulnerable and legitimately dependent by social security policy, could be benefactors who exercise relational forms of agency in Yolŋu domestic moral economies. The inadequate subsistence provided by the Newstart Allowance and the higher rates of the Age and Disability Support Pensions could foster renal patients' allocative power (Macdonald 2018) and could reinforce their ability and obligations to provide for their families. Differential incomes were likely to further bind renal patients, who tended to have greater financial means and accrued greater financial obligations, and their kin who provided them with non-material forms of care.

Yolŋu renal patients receiving the Disability Support Pension and Age Pension could be subject to similar expectations of sharing as described by Julie Finlayson in relation to parenting payments in an earlier era of social security policy (Finlayson 1989, 1991). Based on ethnographic fieldwork conducted in north Queensland in the 1980s, Finlayson argued that parenting payments paid to Indigenous mothers at higher rates than the unemployment benefits paid to Indigenous men created material gender inequalities. Finlayson described the significant claims that men exercised over their wives' and mothers' incomes, which were also recognised by the women. In the early 1990s Francesca Merlan also described expectations among Indigenous people in Katherine that women would contribute a greater proportion of their incomes to household provisioning (Merlan 1991). While parenting payments may have previously been categorised as a form of legitimate dependency in Australian social security policy, since the 1990s parenting payments have been substantially curtailed through the tightening of eligibility criteria, reduction of payment rates and the application of greater levels of conditionality (McKenzie et al. 2016). As with the financial expectations of Indigenous women described by Finlayson and Merlan, among Yolŋu renal patients, the presence of resources themselves could create an obligation to share with close kin. Amongst older renal patients, however, the higher rates of the Disability Support Pension and Age Pension could also intersect with the responsibilities of age and of being a household head. Where Finlayson argued that differential rates of social security could reconstitute gender relations, I argue that through the higher rates of payments distributed to renal patients, the state exploits existing social roles and responsibilities that Yolŋu associate with older age. Moreover, I argue that renal patients' willingness to provide for their families takes on agentive dimensions of taking responsibility for the material needs of kin and of nurturing relationships of mutual care through relational modes of agency.

Paradoxically, Australian social security policy, grounded in a particular intertwining of neoliberal and paternalistic imperatives, is parasitic on Yolŋu practices of hunting, gathering and sharing, constituted through values of material equality and relations of interdependency. Australian social security policy, which distributes welfare through ideas of legitimate and illegitimate dependency, relies on Yolŋu renal patients categorised as legitimately dependent to perform social roles in which they take responsibility for the material needs of their kin in order to construct a subsistence safety-net. As Andrea Muehlebach has convincingly argued in relation to moral economies within Italian society, neoliberal social policy is omnivorous of other social orders that may appear to operate in opposition to it (Muehlebach 2007, 2012). The insufficiency and conditionality of the Newstart Allowance reproduced Yolŋu sharing practices, in contradiction to the objectives of income management. By subverting social security policy agendas that attempt to reshape norms of provisioning and redirect recipients' responsibilities towards themselves and a nuclear family, Yolŋu enable other policy

objectives of achieving a basic subsistence to be realised. Neoliberal and paternalistic Australian social security, through the categories of legitimate and illegitimate dependency, institutionalises interdependencies and social roles in Yolŋu families, and interdependencies between the legitimately dependent and the state.

Compromised subsistence in Yolŋu domestic moral economies

While social security policy could in some circumstances exploit interdependencies and sharing practices in the families of Yolŋu renal patients, living in Darwin could also make Yolŋu domestic moral economies difficult to sustain. Displacement was an economic as well as physical and social experience. The lives of Yolŋu living in Darwin were governed in different ways to the lives of Yolŋu residing in north east Arnhem Land, and as a result, relations and practices of subsistence were altered by urban displacement. In this section I explore how the care of the state for renal patients, through urban displacement, curtailed hunter-gatherer production and could, in some circumstances, compromise sharing practices among kin, threatening renal patients' subsistence.

The curtailing of hunter-gatherer production of foods and medicines

The displacement of Yolŋu to Darwin further compromised hunted and gathered production, in addition to the withdrawal of government financial support for homelands in north east Arnhem Land. Although similar plant, animal and mineral resources could be found in waterways, parks, reserves and verges around Darwin to those found in north east Arnhem Land, such resources were subject to over-extraction. Yolŋu interlocutors described hunting and gathering practices in north east Arnhem Land as usually involving a single small party of kin working together in a particular location. I accompanied interlocutors to collect shellfish, mangrove worms, mud crabs, yams and white clay around Darwin on several occasions, however there were often other parties working in the same locations, usually other Indigenous people who were also visiting from their own remote communities; and such natural resources were often difficult to find. Local Larrakia Rangers[30] report depleted supplies of natural resources throughout Greater Darwin, including in areas in which Indigenous people from remote communities are known to camp. As such resources, with the exception of mud crabs, were not generally commercially harvested in Darwin, they tended to exist

[30] Larrakia Rangers are employed by Larrakia Nation Aboriginal Corporation through government grants and commercial funding. Rangers undertake natural resource management activities, preservation of sites of cultural and natural heritage value and maintenance of town camps around Greater Darwin (Larrakia Nation Aboriginal Corporation 2019).

beyond the realm of government regulation, despite the advocacy efforts of the Rangers[31]. One Larrakia man not working directly with the Rangers explained to me that he had forsaken hunting because 'my stocks are down'. The Northern Territory Department of Health (2018) also advises Darwin residents that fish and shellfish in Darwin Harbour may be contaminated with heavy metals and chemicals. Hub and spoke service delivery models that concentrate government services in Darwin may contribute to strains in the interdependencies of care between people and country in local hunter-gatherer economies.

Restrictions on the means required to consume natural resources in Darwin could further limit access to hunted and gathered resources among my Yolŋu interlocutors. Bans on cooking fires in public places and in the outdoor areas surrounding public housing (Figure 7), and a lack of access to kitchen facilities among hostel residents, threatened our ability to cook hunted and gathered foods in ways which corresponded to Yolŋu tastes, while they were fresh. On one outing at Lee Point Reserve, as two police officers advanced towards our party and another party of Yolŋu camped in the same place, one woman from the other party urged her husband to put their fire out. Her husband, however, was preoccupied with hiding in a tree his spear, with which he had been hunting stingray. After demanding the immediate extinguishment of cooking fires in which shellfish were roasting and threatening us with fines, the police departed.

[31] While there are some limits placed on the harvesting of mud crabs, the lack of regulation of natural resources such as shellfish and yams contrasts with the extensive regulation of recreational and commercial fishing in the Northern Territory (Northern Territory Department of Primary Industry and Resources 2017). Stakeholders described Northern Territory regulatory regimes for fishing as highly politicised.

Figure 7 Hunting and gathering with Yolŋu interlocutors in Darwin

L-R: our party sits behind a sign indicating the prohibition of camping, fires and dogs at Lee Point Reserve; cooking shellfish, catfish and porridge on the side of Channel Island Road.

L-R: Cooked *buny'bu* meat on the side of Channel Island Road; *buny'bu* (longbum) at East Point Reserve. Credit: Stefanie Puszka

Yolŋu interlocutors described impediments to hunting and gathering natural resources in Darwin as necessitating greater reliance on commodified foods, and hence on income; as well as precipitating greater reliance on biomedicine. Although groceries were substantially cheaper in Darwin supermarkets in comparison to stores in remote Indigenous communities (Northern Territory Department of Health 2017), which several interlocutors acknowledged, many expressed similar frustrations to Wapiriny, who lamented to me repeatedly, 'everything costs money here'. In remote Indigenous communities, hunter-gatherer economies address the insufficiency of social security, particularly for those cast as illegitimately dependent, providing them with an additional subsistence safety-net. Yet through the withdrawal of financial support for homeland residents and the

centralisation of government services such as dialysis in Darwin, the state threatens the viability of such ways of life.

Hunted and gathered resources were also available in commodified form through a local informal economy existing in Darwin among Indigenous people from various parts of the Top End. Yolŋu interlocutors knew where, and from whom, they could purchase Tiwi Islands and Yirrkala white clay and Daly River magpie geese in Darwin. Some small suburban supermarkets also retailed kangaroo tails. Interlocutors discussed pre-colonisation ceremonial exchange between Indigenous collectivities across the Top End, and similar practices are documented in the ethnographic literature (for example, Thomson 1949; Williams, N 1986). The commodification of hunted and gathered resources appears to represent a different means of sustaining relations of exchange amongst Yolŋu and other Indigenous people in Darwin.

Hunted and gathered foods exchanged in Darwin at times resembled 'potential commodities' rather than fully commodified goods (cf Appadurai 1986). On one occasion, Yolŋu interlocutors complained of a seller seen to be profiteering from the high price he was charging for zip-lock bags full of white clay, in comparison to other sellers, as the young man was assumed to be capable of full time work in the formal economy, and so could afford to charge lower prices. In this case, my interlocutors appeared to reject a profit motive by a man whose subsistence may have already been assured. On another occasion, I followed Mr Muŋuḻpurr, Wapiriny and their kin around Palmerston, Darwin's satellite town, as they acquired information about where they could purchase magpie geese from a Daly River man who had a freezer full of birds he had hunted on his country. The man explained that he was 'not really selling them', and perhaps was intending to keep them for his own consumption or for distribution to relatives. Although he said he would accept $40 for one, he gifted our party a second goose free of charge. Purchasing commodified hunted and gathered resources, however, still required disposable income, and Yolŋu interlocutors only appeared to occasionally buy such foods and medicines. As I will further explore in following sections, the curtailing of hunter-gatherer production in Darwin could contribute to the inadequate subsistence of many Yolŋu living in the town.

Compromised sharing practices

Impediments to hunting and gathering among Yolŋu living in Darwin were compounded by increased costs of living and household bills that were structured in different ways to living expenses in north east Arnhem Land. As noted in Chapter Five, urban public housing tenants, whose rent was tied to

urban private rental markets and was likely shared among smaller numbers of tenants, were subject to higher rates of rent compared to the tenants of public housing in remote areas. Hostel residents in Darwin paid much higher tariffs than the rent paid by public housing tenants throughout the Northern Territory. The financial costs of displacement included the payment of bond for new public housing abodes and the acquisition of furniture[32]. In remote communities, electricity was paid for in small, regular instalments through power cards purchased at local stores, whereas Darwin residents paid quarterly electricity bills requiring periodic lump sum transfers that were less easily shared among multiple household members.

Despite the likely eligibility of renal patients for higher rates of social security, household bills and reduced disposable income could limit the capacity of Yolŋu living in Darwin to respond to the needs of kin as they arose. Although recipients of the Disability Support Pension and Age Pension were not subject to income management, reduced disposable income could inhibit the ability of Yolŋu to share with kin, precisely at a time when money was most in need. While Yolŋu living in Darwin continued to make requests of one another of money and food, and close relatives sometimes pooled income, interlocutors described sharing practices as compromised by the way that subsistence was structured in Darwin. Ŋarritj, for example, explained to me that Yolŋu living in Darwin were less likely to share food with kin who were not residing with them:

> *It affects Yolŋu society when we move to Darwin. We go back to Elcho – you can walk into a house, go to the cupboard, go to the fridge, ask anyone. You can walk in and say I'm hungry. In Darwin you won't find that because of power bills, water, especially money to cover food and smokes so people in the Darwin community, they say bäyŋu* (refuse)*, always say nothing. Not because of Yolŋu but because of the place we're living, they have to change to adapt that culture, it can affect Yolŋu culture when they come to this life, people will experience issues. It's hard for some, some end up in the longgrass…. That's how hard it is but Yolŋu don't have a choice, especially renal patients. The only choice is to share and love unconditionally, that's what she* (Bu̲lanydjan) *does. I've learnt from her. If I was back in Galiwin'ku I'd get paid, all I'd have to do was get a $50 power card but because of the systems here, I buy her two packets of ŋarali* (cigarettes) *every time I get paid and $100 cash for rent and power. It's coming to terms with a different way of living, different ecosystem.*

Mr Muŋu̲lpurr similarly claimed that 'here (Darwin) we can't get money from family, too hard'. Gutjan also told me on several occasions, 'I don't want to ask family for *rrupiya* (money)', adding that 'in Galiwin'ku family give you *rrupiya*, they want to help. Darwin is too hard'. An evaluation of the Tiwi Dialysis Centre also noted that Tiwi patients reported reduced disposable income when receiving treatment in Darwin, and attributed differences in patients' disposable income in Darwin and on the

[32] New public housing constructed in Galiwin'ku during my fieldwork was allocated to residents by Territory Housing along with some items of furniture and certain appliances, whereas unfurnished public housing was allocated to successful public housing applicants Darwin.

Tiwi Islands to the greater capacity of Tiwi to share resources in their home communities (Gorham 2000). While my interlocutors who had obtained public housing did not express a similar reluctance to offer shelter to kin, the previous chapter also showed that the ways in which the obligations of care were conceptualised in housing policy frameworks and by Yolŋu tenants could similarly result in strains in relations among kin. The more finite nature of money and food in comparison to shelter in one's house perhaps accounted for differences in the capacity of interlocutors to share money and food and extend shelter to kin.

As noted earlier, Nicolas Peterson, in his original formulation of Indigenous demand sharing practices, based on fieldwork undertaken in north east Arnhem Land and elsewhere, described demand sharing as a negotiation of social relations. As the volume of requests made to any individual is likely to exceed their personal means to respond, according to Peterson, demand sharing necessitates strategies for managing of requests (Peterson 1993). My fieldwork was in the main limited to Darwin, and so my claims that Yolŋu living in Darwin are more likely to refuse the requests of kin compared to material requests that Yolŋu made of one another in north east Arnhem Land are limited to my interlocutor's claims. Nevertheless, ethnographers of Australian Indigenous societies have often reported the complaints of their interlocutors about social pressures resulting from the density of requests in larger communities and towns in which greater numbers of kin may be present (eg: Folds 2001; Martin, DF 2011; Myers 1986). I argue that social pressures of kinship in an urban area were likely further compounded by reduced disposable income and the way that living expenses were structured, which could compromise the capacity of my interlocutors to respond to requests. While Peterson and Taylor (2003) describe the resilience of Indigenous demand sharing practices across Australia, others have described their adaptation in response to capitalist development and competing pressures (Austin-Broos 2003; Macdonald 2000; Sercombe 2008). Impediments to sharing could curtail the ability of interlocutors to exercise relational modes of agency.

It was common for Yolŋu renal patients in Darwin who required sums of money to pay bills and other living expenses, and who were unable or unwilling to procure funds from relatives, to turn to payday lenders. Several such lenders had established shop fronts across the town. Interlocutors used small loans from these lenders to cover daily living expenses when they had run out of money ahead of fortnightly social security payments, as well as to purchase phones, televisions and tablets. Payday lenders tended to charge high rates of interest, in addition to large establishment fees and other additional fees. One such lender frequented by some interlocutors offered a loan of $300 that required a total repayment of $384, and a loan of $1500 for a total of $1980 in repayments. Financial deregulation and the rapid expansion of consumer credit to previously excluded populations,

embodying a neoliberal ethic, has produced new forms of (inter)dependency and indebtedness (Rona-Tas & Guseva 2018).

One day, when I was assisting Annie with her Disability Support Pension application, she mentioned that the new birth certificate we were seeking for her would also enable her to apply for a small loan from a payday lender. She planned to use the loan for basic living expenses because, she said, 'I don't wanna ask family'. It was a phrase that she often repeated, especially when asking me for assistance, perhaps fearing their rejection. Interlocutors' financial debts to payday lenders can be seen to be a product of impediments to sharing practices, which compromised their subsistence, and as further compromising their ability to respond to the needs of kin.

Inadequate subsistence and strains on interdependencies of care

Annie often spoke of her hunger. At Helen's unit Annie sometimes sought food and a shower, but she admitted that 'sometimes there's no food (at relatives' houses)', and she attempted to get by just by consuming small amounts. Yinin, who was also present during many of our discussions, and knew of Annie's trials, elaborated, 'sometimes she tries to think of people she could go to for help but she always ends up at Helen's place, she has no one else'. Annie had attempted to seek help from other relatives previously, but, Yinin continued, 'sometimes the people are not home, it's hard to get into a place to change *girri* (clothes), shower, get *ŋatha* (food)… She walks away feeling not wanted, alone. Some people tell her to leave. She thinks, how did I get into this?'

Renal patients such as Annie who were unable to mobilise welfare resources through legitimate dependency status were likely to receive little social security income. However, it was the compounding of low incomes with the curtailing of hunter-gatherer production and sharing practices that threatened their subsistence. The inadequate subsistence of renal patients could further upend practices of generalised reciprocity within relations of care in Yolŋu families. Renal patients such as Annie could be subject to interconnected experiences of bodily, social and economic precarity.

Annie was awaiting the arrival of her sister in Darwin, who she explained would care for her. Annie's sister would liaise with her doctors to get a better grasp of Annie's condition and treatment, and together they would decide whether Annie would seek a kidney transplant, pursue dialysis in north east Arnhem Land or remain in Darwin, Annie told me. However, Annie's sister faced competing responsibilities of caring for Annie and her new baby; and Annie was unable to offer her sister and sister's children accommodation. Notably, Yolŋu with children in their care who found themselves

sleeping rough were likely to have their children removed by child protection services. Annie continued to await her sister's arrival well after my fieldwork concluded. Of her lack of carers and visitors, Annie mourned, 'it makes me getting weak'. Her lack of care made her feel 'gora' (shame), she told me.

For a brief period, Annie was cared for by another older sister's daughter. The 19 year old woman had resigned from her job at a Darwin-based Indigenous organisation and was caring for both Annie and her mother's father, who was also a renal patient, at her grandfather's public housing unit where they all resided. For perhaps a month, Annie and her sister's daughter seemed inseparable, and the young woman accompanied Annie to her medical appointments as well as in other movements across the town. The young woman also assisted her grandfather with showering, by taking him out in his wheelchair and by cleaning the unit while she resided there. However, the young woman had refused her relatives' request to become a carer for her grandfather, she explained to me, because her mother was the one receiving the Carer Payment that he attracted. She discussed plans to apply for a Carer Payment in recognition of the care she provided to Annie. However, after she became aware that Annie was ineligible for financial support for a carer, on account of Annie's relatively young age and physical status as a relatively able-bodied patient, the young woman returned to her homeland. Her desire for remuneration for domestic labour through the Carer Payment may have reflected the formalisation of care work in the families of renal patients discussed in Chapter Three, as well as the increased costs of living and reduced capacity to obtain money and food from kin in Darwin.

Domestic care, premised on relations of intergenerational interdependency and generalised forms of reciprocity in Yolŋu domestic moral economies, could be difficult to sustain in the presence of inadequate subsistence. Relations of care for relatively young renal patients such as Annie were more difficult to assimilate into Yolŋu domestic moral economies in which care was enacted through intergenerational relations and figured as an expression of respect for elders. End stage kidney disease could disrupt lifecourses and rupture social roles in ways that left some younger patients without carers. Although younger patients tended to describe themselves as requiring care, and many were receiving some form of care from relatives, not all of them had stable carers. Families did attempt to provide care for younger patients, and younger interlocutors were often cared for by marriage partners and daughters. However, the reduced capacity of younger patients to mobilise welfare resources such as Disability Support Pensions, Age Pensions, Carer Payments and social housing could further strain the interdependencies and reciprocities of care in Yolŋu domestic moral economies.

My interlocutors further demonstrate how caregiving in Yolŋu families is sustained through domestic moral economies and through the agency of care-givers and receivers. Securing the basic material and non-material needs of life in the context of conflicting values and imperatives in Yolŋu families and through the governance of social security requires considerable work. Annie's predicament also illustrates how displacement can compromise the material subsistence of renal patients' families, and the relations of care and reciprocity that sustain it. As noted earlier, there are some tendencies within the anthropology of care to romanticise caregiving, and few ethnographies of care have considered absences and limits of care. However, as Clara Han notes in her ethnography of care and financial indebtedness in Chile, examining the limits that families and states place on care can be illustrative of how obligation and responsibility is constituted and how compromises are made (Han 2012). The strains in the social fabric of Yolŋu families that I have described show how material resources and the negotiation of economic obligations and entitlements in families are central to sustaining care.

Strains in the social fabric of Yolŋu domestic moral economies that made one a particular kind of kinsperson in relation to others could threaten the integrity of one's being. Impediments to sharing, inadequate subsistence and strains on interdependencies of care could leave renal patients such as Annie feeling devalued or experiencing 'shame'. Annie admitted that she frequently skipped dialysis. Missed dialysis treatments could compromise patients' overall health, placing pressure on their hearts and livers. It could result in hospitalisation, and over a longer period, could contribute to a reduced lifespan (Obialo et al. 2012; Tentori et al. 2007). For interlocutors who decided to cease treatment, two weeks without dialysis could be sufficient to end their lives, and for those who had not well adhered to treatment, the palliative period could be further reduced. A lack of adherence to treatment could also make patients ineligible for remote dialysis services and kidney transplants when they became available, due to their compromised health (see Chapter Seven)[33]. Annie's lack of adherence to treatment was a product, at least in part, of her lack of fixed address and insecure living conditions. Her propensity to miss treatment may have also reflected an absence of care and an experience of a loss of personal substance and agency, understood to be a product of positive social relations. In some cases, urban displacement could threaten the social fabric of Yolŋu domestic moral economies, compromising not only the material subsistence of Yolŋu families but also the capacity of families to provide their members with end stage kidney disease with a life worth living.

[33] Although there were no renal services available at Milingimbi during my fieldwork, Annie expressed a desire to take part in a pilot of dialysis at Galiwin'ku, where some of her relatives resided.

Conclusions

In Chapter Three I argued that in Yolŋu domestic moral economies, relations of care are constituted through interdependencies and material and non-material reciprocities in the families of renal patients. In this chapter I have shown how interdependencies in Yolŋu families are constituted through differential rates of social security and different physical abilities to hunt and gather among renal patients and their kin. I have discussed how practices of sharing money and food are integral to the performance of social roles, the production of social value and the pursuit of a basic subsistence.

Over the course of the last three chapters, I have considered how neoliberal and paternalistic values in Australian health and social policy interact with Yolŋu values of care and Yolŋu domestic moral economies. I have explored the ways in which the basic needs of life of Yolŋu renal patients and their kin become legible and are governed in health and social policy, through particular constructions of care and dependency. This chapter has attended to the ways in which care and dependency are constituted in Australian social security policy, and how such constructs articulate with the values and practices of care in Yolŋu domestic moral economies. As with Northern Territory housing policy discussed in the previous chapter, through concepts of care that categorise people seeking welfare as either legitimately or illegitimately dependent, the suffering and marginalisation of renal patients gains particular salience, while the everyday subsistence struggles of their carers and other kin often do not. In Yolŋu domestic moral economies, however, legitimate dependency status could be transformed into responsibilities to others. The Disability Support Pension and Age Pension, positioned as the care of the state to those considered legitimately dependent, were transformed through interdependent relations of kinship in Yolŋu families into renal patients' care for their kin. While social security policy expresses value in self sufficiency, it is parasitic on Yolŋu practices of hunting, gathering and sharing in the construction of a subsistence safety-net and the promotion of food security. For Yolŋu families, realising a basic subsistence requires subverting other social security policy agendas that attempt to curtail sharing and exercising relational modes of agency. Realising relations of care requires resisting social security policy attempts to compel the participation of carers in the formal economy. My analysis in Chapter Five and Six illustrates how asymmetric interdependencies between Yolŋu families and the state in providing renal patients and their kin with care have become particularly salient and yet also particularly fractious in neoliberal times, through the curtailing, means testing and conditionalising of state welfare.

Such interdependencies of care between Yolŋu families the state are particularly evident in the chasms through which some Yolŋu fall when health and social policies threaten the social fabric of domestic moral economies on which Yolŋu and state policy agendas both depend. The displacement of renal patients from remote communities could curtail sharing practices and could further jeopardise hunter-gatherer production, threatening subsistence. While income management represented a deliberate attempt within social security policy to limit Indigenous practices of sharing among Newstart Allowance recipients, I suggest that the unintended consequences of urban displacement, and the ways that my interlocutors' lives were governed in Darwin, could have a greater impact on the capacity of Yolŋu to share money and food. For some patients, such as Annie, impediments to sharing and inadequate subsistence could manifest in absences of care and feelings of devaluation. Younger patients like Annie, whose legitimate dependency status in welfare programs was less certain and whose lifecourses were ruptured in a way that could prevent some from taking up the responsibilities associated with youth or middle age, could be particularly afflicted by intertwined bodily, social and economic precarity.

Social security benefits and obligations are closely linked to citizenship rights and responsibilities, and the nature and extent of social security payments are often held to be indexical of what kind of society we imagine ourselves to be (Esping-Andersen 1990). Interdependent relations between state health and social policy agendas and Yolŋu families have implications for how we conceptualise Indigenous citizenship of the Australian state; and what forms of social value might be legitimated in government policy agendas. In the following chapters, I return to the articulation of health policy with Yolŋu relations of care to explore moral, legal and political implications of the interdependent relations of care between Yolŋu and the state.

Chapter Seven

The politics of remote dialysis: Responsibilities, liabilities and threats of care in Northern Territory renal services

Mr Muŋuḻpurr seemed particularly buoyant over the phone one morning, urging me to meet him as quickly as I could at the Purple House office in a suburban shopping centre. A long-anticipated Galiwin'ku patient meeting was about to take place. Miwatj Health, an Aboriginal Community Controlled Health Organisation based in north east Arnhem Land, was running a pilot of 'reverse respite' dialysis at Galiwin'ku, a major community located on Elcho Island, in conjunction with Purple House. Some of the many patients connected to the remote community were being given the opportunity to return to Galiwin'ku and receive dialysis there for two-week stints. The Galiwin'ku dialysis facility (renal ready room), which was usually unstaffed, and the two dialysis chairs inside it, which were usually unused, were filled with one nurse and four rotating patients for two week periods. While Miwatj Health would fund the nurses' services, contracted through Purple House, the Arnhem Land Progress Aboriginal Corporation (a Yolŋu business that owned and ran community stores) paid for patients' travel. The ten patients packed into the tiny office and one patient who joined the meeting via teleconference from the hospital were asked to determine which of their number would fill the four available places in each of two trips.

Following a lengthy and spirited discussion, patients chose those within their number who would participate in the pilot over the coming months. Those selected to take part in the second trip, which was to coincide with a funeral in the community, were chosen on the basis of their relation to the deceased[34]. Participants in the meeting rationalised their choice of candidates for the first trip as

[34] In north east Arnhem Land, funerals are often held many months after a person passes away.

those who were not planning to attend the funeral, were seen to have authority to talk on behalf of others, and had been involved in advocacy efforts to expand dialysis services in north east Arnhem Land. Some of those who were nominated, however, were unable to take up the opportunity after doctors assessed their overall state of health as being 'too high risk' to receive treatment outside of Darwin. At the time of writing, five of the Galiwin'ku patients undertaking treatment in Darwin at the time of the pilot had passed away, including one woman who was unable to take up her place in the pilot following medical advice. The pilot would have enabled her to attend her sister's funeral and to visit other relatives living in the community for the last time.

Multiple values of care competed in determining the allocation of dialysis chairs in the Galiwin'ku pilot. In this chapter I explore the contending values of care attributed to dialysis performed on country by Yolŋu and in healthcare systems. I analyse the interaction of the social constructs of medical risk and professional duty of care with Yolŋu values and practices of care. I consider how the construct of medical risk structures the responsibilities and liabilities of health professionals and the obligations and entitlements of patients in particular ways, and casts remote Indigenous communities as places of high risk to patients' health and lives. I analyse the implications for Yolŋu and for healthcare systems of contending values of care and contending perceptions of threats to patients. I argue that the construct of medical risk fails to apprehend the existential threat that urban displacement poses to Yolŋu patients. Through the constructs of medical risk and duty of care, Northern Territory renal services cast patients as dependents of healthcare systems and fail to realise the value of the interdependent relations between healthcare systems and Yolŋu families in caring for patients.

Prior to the announcement of the new funding arrangements for remote dialysis described in the Introduction, I accompanied Mr Muŋul̲purr and some of the other patients taking part in the Miwatj Health pilot of dialysis at Galiwin'ku. In this chapter I draw on ethnographic fieldwork conducted in conjunction with the pilot and interviews with health professionals and senior Northern Territory health policymakers. After briefly discussing my approach to medical risk and professional duty of care as social constructs, I explore Yolŋu renal patients' experiences of the Galiwin'ku dialysis pilot as fostering bodily, social and biomedical health. I then explore how a renal nurse experienced the pilot as enhancing her professional autonomy and increasing her professional responsibilities, in comparison to dialysis performed in hospitals. I go on to explore narratives of medical risk in renal services among health professionals and health policymakers, how patients' access to remote renal services is governed through the construct of medical risk, and how medical risk casts responsibilities and liabilities in Northern Territory healthcare systems. In the final section I show how urban models

of dialysis emerge from Northern Territory renal services' inability to recognise the value of interdependencies between Yolŋu families and healthcare systems in sustaining patients' health.

Approaching medical risk as a social construct

The concept of risk in the English language, although originating from Latin roots, can be historicised within European modernity and the emergence of technocratic systems premised on abstract forms of reasoning (Beck 1992; Giddens 1990; Gifford 1986). Medical risk can be understood as a social construct historically and culturally embedded in a particular conceptualisation of health and disease, and as a normative concept that emerges when uncertainties are attributed negative value in healthcare systems (Honkasalo 2006; Samimian-Darash & Rabinow 2015). Risk factors represent particular configurations of temporalities, potentialities, practices and statuses in a biomedical regime of value and valuation. As Hannah Bell and colleagues (2019) argue, medical risk factors are technologies of clinical decision-making that construct narratives around categories of genetics, biology, behaviour, culture, socio-economic circumstances and, we might add, geography. In this chapter I approach medical risk as imbued with particular values of care associated with patients' biomedical safety and health professionals' liability. The medical risks ascribed to renal patients by medical protocols and health professionals, including the possibility of hospitalisation and death, can be approached as one configuration of possibilities. Patient deaths on country and in hospitals may carry different social meanings and implications for patients and health professionals.

The social construct of medical risk structures legal, moral and political responsibilities in healthcare systems (Zinn 2012). Medical risk defines categories of normality and abnormality, and may be deployed to establish patients' trajectories through healthcare systems (Anderson, I 1995; Clarke et al. 2010). Responsibilities for risks can define one's sphere of belonging and accountability, and relationships to others (Hage & Eckersley 2012; Trnka & Trundle 2014). In this chapter I explore how the risks and responsibilities of renal care order the relationships and boundaries between renal patients and healthcare systems, legally and institutionally. I draw on the concept of professional duty of care to refer to health professionals' and healthcare systems' responsibilities to patients. As I will explore further below, health professionals and health policymakers invoked the concept of duty of care at times to express a sense of responsibility for patients beyond their job descriptions and hours of work; and the concept duty of care was deployed to manage and mitigate medical risks.

Realising biomedical and Yolŋu ideals of health: Yolŋu renal patients' experiences of the Galiwin'ku pilot

It was with some trepidation that I set off from Galiwin'ku with Mr Muŋul̲purr, his wife and some of her sister's daughters to their relatives' homeland. While Mr Muŋul̲purr and I had come to Galiwin'ku for the dialysis pilot, Mr Muŋul̲purr also had other business to attend to on Elcho Island. Despite the assurances of my companions, I was not confident that the aging, low clearance, two wheel drive ute I'd hired at the Galiwin'ku airport, the only vehicle available, was adequate for the task of traversing the sandy road. Nevertheless, we soon arrived, thankfully unscathed, at the homeland which stood on land Mr Muŋul̲purr referred to as his *märi*. One large house and several tents stood overlooking a sandy beach. In the shade of a tree, an elderly man was carefully completing a painting while several children looked on. Mr Muŋul̲purr pointed out the homeland's *djuŋgaya* (caretaker), a middle aged man, and introduced me to an elderly woman who, he explained, I should also call *märi* through our fictive kin relations. Sitting in a grassy area besides the graves of several of Mr Muŋul̲purr's ancestors, we were treated to a communal meal by our hosts. Turtle, caught by young men of the homeland, cooked with rice, was consumed directly from pots, along with chilled water from a local fresh water spring, sipped communally from plastic bottles. Later in the afternoon, Mr Muŋul̲purr arranged for one of the older men and some of the younger women to take me over to an important site on the mainland in their small boat, showing me a resting place of the Djaŋ'kawu sisters of a fabled Yolŋu creation story. Mr Muŋul̲purr himself opted to remain at the homeland, explaining that I would be traversing mangroves infested with biting midges, which were to be avoided by renal patients. Much later, I returned to Galiwin'ku, along with all of the children and the other women, while Mr Muŋul̲purr took part in a men's ceremony at the homeland.

…….

As previous chapters have discussed, through *märr,* Yolŋu interlocutors expressed one's presence on country and the quality of one's social relations as shaping personal vitality. *Märr* foregrounded social as well as physical experiences of health and disease. Hunted and gathered foods that invoked relationships between people and country and sharing practices were considered essential to personal vitality. Biomedical treatment that removed pain and discomfort, including dialysis, could be assimilated into Yolŋu conceptualisations of health and broader life projects. Receiving dialysis treatment through urban displacement and sedentarisation, however, was said to minimally sustain renal patients without inducing *märr* or a full state of health. While patients displaced to Darwin could

maintain relationships with kin in various ways, as previous chapters have shown, for Yolŋu, realising social value through relations of care in domestic moral economies ultimately required being present on country.

End stage kidney disease in the absence of the social suffering of urban displacement was not experienced in physically painful ways or through a loss of agency by Yolŋu patients. Mr Muŋul̲purr, after returning to Darwin from the Galiwin'ku pilot, described being cared for through intersubjective connection to kin, country and ancestors on Elcho Island, which he described as leading to positive feelings and sensations and improving biomedical metrics of his health:

> *When I miss renal in Darwin I feel sick, but not back in Galiwin'ku.* (In Darwin) *I have pain, I don't feel like eating, I don't feel like walking.* (In Galiwin'ku) *that's because you're home and you can feel the atmosphere and feel the voice of the wind talking to you and saying 'I'm here', and you say to yourself 'I should be back here with my great great great ancestors because the spirit is talking to me...' I felt, bin feeling when we first flew in* (to Galiwin'ku)*, I was feeling like my plane was shaking. It was smooth but I felt myself like that the island was laughing for me, the island could hear that I was coming... the sand, the sea will laugh for us and we'll talk to them and everything will be run smooth, no high blood pressure, no salt, no sugar. They'll laugh every day* (if we go back).

Yolŋu interlocutors described remote renal services, complemented by the care for patients within domestic moral economies on country, as improving the health of individual and social bodies.

Patients I knew appeared to be more physically active on Elcho Island during the pilot than when residing in Darwin. An older participant in the Galiwin'ku pilot, who appeared frail in Darwin and didn't seem to go out often outside of her dialysis appointments, walked from Galiwin'ku to a homeland with which she was connected and back, a journey of approximately 10 kilometres. Yinin recounted the enhanced agency and productivity of another patient who returned temporarily to Galiwin'ku:

> *When I was out at Galiwin'ku, and one renal patient, she was walking up the street. She was walking, she was walking. I saw her driving, I said 'Hey! Who's that woman, who's that lady, I know that lady'. She had to walk, she had to walk from the community, the township all the way up to the outstation, to her homeland where the barge landing is. And hunting, she went hunting. She went hunting with the family. She got on the dinghy, the boat. They went across to this other island to grab, get fresh oysters. Yeah! She came back and she said to me 'hey, do you want some oysters, you want some oysters or what? Fresh oysters'. 'True? Did you go hunting?' Yes. And she was making damper. She was going collecting firewood, she did all the work. But here* (Darwin) *nothing, nothing. Yes. Here, when they are here, they are looking, waiting for carer to come in to care for them.*

Yolŋu undertaking treatment on country attributed their renewed agency to the ways in which physical and social geographies were experienced.

Receiving treatment and care on country could also improve the health of patients in biomedical terms. Evaluations of remote dialysis services report that patients undertaking treatment in their home communities have better adherence to treatment, better biomedical health outcomes and fewer hospital admissions (Gorham 2000; Gorham et al. 2017; Marley et al. 2010). Health professionals involved in the provision of dialysis in remote areas likewise observed dramatic improvements in patients' health when they returned to their communities. One manager recounted second-hand a nurse's observation of her patients during another stage of the Galiwin'ku pilot:

> *…what they did was they opened the home dialysis unit that they've got over there* (in Galiwin'ku) *and a couple of guys came over who hadn't been back on country for years because there was no dialysis. And she said that the change in these two gentlemen, one is particular, one was immobile but the other one was not and the changes in him and his actual physical health while he was there was incredible… she said his blood pressure went down and she had to take him off his meds and all sorts of things like that you know.*

Although high rates of end stage kidney disease amongst Indigenous Australians generally correlate with remoteness (Australian Institute of Health and Welfare 2015a; Cass, A et al. 2001), Indigenous people residing in Northern Territory homelands have been shown to have better biomedical health outcomes including reduced risk of kidney disease (Burgess et al. 2009; Campbell 2011). Homelands usually exist on country classified as 'very remote', over which residents have recognised rights and responsibilities. Yolŋu interlocutors described homelands as lacking the social stresses of larger communities. As Victoria Burbank also notes more generally, chronic psychological and social stress, of the kind experienced by displaced patients, is recognised in biomedicine as causing chronic disease and other poor biomedical health outcomes (Burbank 2011). Social dimensions of end stage kidney disease were fundamental to patients' experience of renal disease, as earlier chapters have shown, and evidently also impacted on biomedical dimensions of patients' health. Dialysis provided through urban displacement denies the sets of social relations between patients, their kin, country and ancestors that provide them with the basic needs of life and make them well, in both Yolŋu and biomedical terms.

While the Galiwin'ku pilot presented a rare opportunity for patients from the community and associated homelands to undertake treatment there, it was not uncommon for renal patients to undertake unauthorised travel back to their communities. Patients appeared to be particularly compelled to return to their kin and country when relatives' funerals were taking place. Patients who returned to their communities often did not clear their travel with renal service staff and, unable to dialyse, missed treatment. After they became critically unwell, they were medically evacuated back to Darwin and often hospitalised, at large biomedical risk and large financial cost to healthcare services.

Their actions illustrate that for some, the care of kin and country are more highly valued than the biomedical risks of missed treatment.

Medical risk, responsibility and liability in Northern Territory renal services

Narratives of risk in remote renal services amongst health professionals and policymakers

The morning sun was already piercing my vision through the trees when Marion, a renal nurse, arrived to pick up Mr Muŋuḻpurr and me from his father in law's house at Galiwin'ku for his dialysis appointment. Marion had come earlier, but Mr Muŋuḻpurr had told her to return later, at the agreed time, and when he was ready to get up. We climbed into the health service's Getz that looked like it had seen better days and slowly made our way to the residence of Ŋathi, Marion's other patient for that morning.

At Ŋathi's house, Marion gingerly knocked on the door, without receiving a response, while Mr Muŋuḻpurr and I waited in the car. She tried again with slightly more force, as Mr Muŋuḻpurr reached over to the driver's side and blasted the horn, and yelled Ŋathi's name repeatedly at full volume, but without success. When other enquiries did not lead us to him, Marion despaired, 'where could he be?', a hint of urgency in her voice. When Ŋathi eventually phoned Marion to tell her he had walked to the renal ready room and was already there waiting for us, she seemed highly relieved. She later confessed to me,

> *Well if some clients are diabetic and they come in, haven't had their breakfast because there was just nothing there and they have a low blood sugar level they could slip into, you know even before I pick them up at home. So actually I was thinking when Ŋathi wasn't there, not knowing Ŋathi well, would have been the second time I see him today. And briefly I, I thought, oh not knowing this person, there was when I knocked on the door, there was no response and I listened and you know the window was open and there was no breathing sounds, I thought what if...*

Having established Ŋathi's whereabouts, Mr Muŋuḻpurr convinced Marion to make a slight detour on the short drive to the renal ready room. Marion complained that 'we're not really supposed to take this car off the bitumen', but obliged anyway. Mr Muŋuḻpurr wanted to point out to me his old house, which he'd had to abandon when he moved to Darwin for dialysis. It was a large yellow building with a verandah all the way around, and could boast some of the best views in town, sitting on top of a cliff and looking out over the water. Mr Muŋuḻpurr drew my attention to two blue and yellow painted

poles standing in the back yard. 'I put those up, that's a memorial to my mother', he told me. Mr Muŋuḻpurr's mother was connected to clans that were represented by blue and yellow colours, I was later to learn.

The renal ready room was a small demountable building resembling a shipping container at the back of the old clinic, a familiar structure in the Northern Territory known locally as a 'donga'. Like other renal ready rooms, it was identifiable by its ochre and cream colour scheme. On the inside, two dialysis chairs faced a window looking out over a bay, affording a magnificent view of the sparkling water and a sandy beach further along the island. Mr Muŋuḻpurr pointed out his *märi* country across the bay.

After connecting Mr Muŋuḻpurr and Ŋathi to the machines, Marion dubbed me her 'renal assistant'. She seemed to appreciate having a second set of hands, explaining that she couldn't leave the renal unit while the patients were dialysing. Thankfully, this involved little more than making breakfast for the patients.

After the patients had nodded off to sleep and Marion had finished recording notes in their files, we shared a cup of tea in the mid-morning sun on the front verandah of the renal ready room. With only the flywire screen separating us from the patients, Marion reflected on her work while keeping one ear trained on the patients, as the machines quietly hummed in the background.

Marion described enjoying the autonomy and the pace of remote renal nursing. Stopping for a cup of tea would have been impossible at the hospital where she usually worked, she admitted, but in other ways, working in a remote renal ready room required more of her. Remote dialysis afforded much more freedom than the rigid policies and procedures and measures of 'quality control' of a hospital renal ward. However, with greater autonomy came greater responsibility; or alternatively, with the rigidity of bureaucracy came protection:

> *…Because you don't have the clinical backup you know, you don't have the button in the wall if you want to have a medical code to call. At the* (hospital) *clinic there's a red button, you press it, the team comes and you're rescued. But here there's no button so you have to always think ahead.*

However, Marion also admitted that some things could not be predicted or mitigated – such as the heart condition of one of her patients, which she described as a 'ticking time bomb'. Her underlying fears may have been heightened by the story told to me by several other renal nurses, of another renal patient who had a heart attack in another remote community, hundreds of kilometres from a

hospital, and passed away. Some narrators added that the heart attack had not occurred while the patient was dialysing, but nevertheless was indicative of the kinds of risks that renal patients returning to remote communities posed.

…….

As Marion's narrative demonstrates, the medical risks of remote dialysis had a visceral presence in the habitus of health professionals and health policymakers who mediated access to remote dialysis services. Administering a specialist, highly technical treatment to patients with serious medical conditions in locations far from hospitals weighed heavily on many of those with whom I spoke. As Kaufert and O'Neil (1993) have observed, medical risk can work through an affective register of fear. Marion's experience of the Galiwin'ku pilot contrasted substantially with that of Mr Muŋulpurr.

Health professionals and health policymakers described the medical risks of dialysis in remote areas as pertaining to patients' bodies, behaviours and geographies. Medical risks seen to be embodied by patients could indeed be severe, including the possibilities of medical evacuation and death. The most significant risks were seen to inhere in the elevated risk of cardiac arrest amongst people with end stage kidney disease[35], the possibility that patients would not adhere to treatment and the likelihood that patients would be subject to frequent medical evacuations. The potential for exposure to infectious diseases presented by crowded housing conditions was described as presenting a further risk to patients, who had compromised immunity. Practices of demand sharing in the context of poverty were also thought to present a risk of inadequate nutrition. Such narratives of risk in remote communities were notwithstanding the conditions of patients' lives in Darwin, in which many also lived in crowded housing and faced food insecurity, as previous chapters have discussed. Risk narratives were animated by the dangers and instabilities of frontiers of governance. The absence of hospitals, of other specialist health services and of adequate housing in remote communities, in concert with the risks seen to inhere in patient sociality, were argued to pose dangers for patients in such locations.

Discourses that worked to locate medical risk in the social geographies of remote communities often contained implicit narratives of the poverty and marginality afflicting patients' health and lives. Narratives of risk articulated by health professionals and policymakers often drew on the concept of the 'social determinants of health'. Offering an explanatory model of structural factors impacting

[35] International scientific literature shows that cardiac arrest is a major cause of death amongst people with end stage kidney disease (Kim & Parekh 2015; Zachariah et al. 2015).

biological health, the 'social determinants of health' concept has been popularised in Australian healthcare, and particularly in Indigenous health (Carson et al. 2007; Chenhall & Senior 2017; Kowal 2015). During my fieldwork, Miwatj Health hosted a forum on the social determinants of health, at which remote renal services were a major agenda item, and health professionals and policymakers frequently referred to the concept in interviews. One senior policymaker described the impact of social determinants of health on end stage kidney disease at length:

> *The high rates of kidney disease and the emerging rates of type two diabetes in young people, it's like the ultimate end game of incredibly poor social determinants, you know, the multiple causes of social determinants, the overcrowded housing, poverty, food insecurity, racial discrimination, low levels of education and disengagement which relates to overcrowding of the houses, that's a significant factor in terms of school attendance, low birth weight, high rates of smoking, you know multiple insults that are occurring obviously chronic stress, chronic inflammation, there's just multiple insults that are occurring from you know when a child is in utero, early childhood, young adulthood and all of those are combining to then create this extreme rates of kidney failure and you know it's terrible…. it's all about disadvantage, Aboriginal people in the Territory do have the greatest disadvantage with remoteness being a disadvantage… Ongoing multiple challenges and, without those issues being effectively addressed the health system is just gonna have to keep working with people to try to, you know, try and help them manage their kidney failure as much as possible.*

In this narrative, through heartfelt concern, a panorama of remote Indigenous communities emerges as places of disadvantage and as places in which biomedical health is difficult to govern. Notably, this interlocutor does not blame either patients or healthcare providers for these conditions. By locating the ultimate causes of illness in structural factors present in remote communities, however, residence in a remote community itself becomes a risk factor. As Daniel Fisher (2015) argues, remoteness functions as a metric of disadvantage in Indigenous health policy discourse.

Health professionals and policymakers who described risky social geographies in remote Indigenous communities drew an implicit contrast with urban hospitals. While renal patients who were displaced from remote communities to urban areas for treatment could also suffer poor health, hospitals figured in Marion's narrative as places in which risk was more governable. In risk discourse, hospitals and their affordances of 'buttons in the wall' could more easily and rapidly respond to biomedical risks to patient health. In hospitals, liabilities could also be more readily dispersed within healthcare systems, horizontally and vertically. Risk discourse among health professionals placed value on a particular form of patient safety and on dialysis treatment provided in urban areas.

The governance of remote renal services through the construct of medical risk

Discourses of risky social geographies among health professionals and policymakers and the value they ascribed to patients receiving treatment in or near hospitals worked to govern the distribution of dialysis services. Patients were triaged through medical protocols that prohibited unwell renal patients who were considered to be 'medically unstable' from receiving treatment in remote areas. 'Medical instability' was a concept that remained undefined in protocols and open to interpretation. Its lack of definition could be mobilised to deny or grant permission to patients to undertake treatment in remote areas. The category of medical instability paralleled narratives of remote communities as frontiers, in which stable governance was difficult to achieve. Patients were also provided with medical advice about returning to their communities that addressed the risks seen to exist in the presence of infectious diseases and in patient sociality. Some health professionals described advising patients against returning to remote communities for brief visits when they had underlying heart conditions or during influenza outbreaks in communities. Some patients were strongly advised to avoid ceremonies due to the increased risk of an outbreak of infectious disease that large gatherings could present. The construct of medical risk informs the distribution of remote renal services among patients.

Medical protocols governing the distribution of remote dialysis chairs could operate through the governance of patient behaviour. Although medical protocols governing the distribution of renal services did not directly govern patient adherence to treatment, patients who had missed treatment in Darwin were unlikely candidates for remote dialysis services when services were available due to their likely poor health. Medical protocols could be mobilised to reward patients who adhered to treatment and medical advice and could penalise patients whose behaviour was seen to create risks. Health professionals at times attempted to bargain with patients by offering to assist them to return to their communities for a few days between dialysis treatments if they better adhered to treatment and nutritional advice.

While kidney transplantation is considered to be the optimal treatment for end stage kidney disease in biomedical conceptualisations of health (McDonald & Russ 2002), studies show that access to kidney transplants amongst Indigenous Australians is underscored by a similar politics of behaviour encapsulated in discourses of medical risk. At the time of my fieldwork, multiple health professionals reported to me that only four renal patients in all of the Northern Territory had been wait-listed for a kidney transplant. Inequitable access to kidney transplants amongst Indigenous Australians with end stage kidney disease in comparison with non-Indigenous renal patients is not explained by clinical

factors alone (Khanal et al. 2018). Kidney transplant recipients are required to adhere to a strict regime of immunosuppressant medication for the life of the organ. Inequitable access to kidney transplants amongst Indigenous Australians has been associated with nephrologists' concerns about the risks of poor transplant outcomes amongst Indigenous patients living in remote areas and attitudes about Indigenous patients' perceived poor adherence to treatment (Anderson, K, Devitt, et al. 2012). The distribution of both kidney transplants and dialysis services in remote areas among patients was mediated by perceptions of medical risk in remote communities within healthcare systems.

Responsibility and liability in remote Northern Territory renal services

The risks seen to exist in the social geographies of patients by health professionals and policymakers cast the responsibilities of healthcare systems to patients in particular ways. The responsibilities of renal services to their patients, as described by health professionals and policymakers, were considerable and took on compassionate and paternalistic registers of care for the vulnerable. Some health professionals described their 'duty of care' to patients as leading them to work unpaid overtime to ensure patients completing dialysis late at night did not miss the patient bus. A broader sense of 'duty of care' could a lead a nephrologist to express concern for patients' mental health. Through a sense of 'duty' to patients, a senior health policymaker described imperatives to better integrate renal services and other healthcare services accessed by renal patients with comorbidities in order to improve the overall accessibility of healthcare. Through a sense of duty of care to the vulnerable, health professionals and policymakers expressed extensive responsibilities over the health and lives of patients.

Conceptualisations of patient vulnerability and staff responsibility amongst health professionals and policymakers could cast patients as dependents of healthcare systems. It did not matter whether patients were blamed for their failure to take responsibility for their own health, or whether medical risks were attributed to structural inequalities in their lives. The possibility that patients would be unable or unwilling to fulfil their own responsibilities, constructed as adhering to treatment and medical advice, was considered to legitimate the assumption of greater responsibility within healthcare systems. Patients who undertook unauthorised travel to return to their communities and missed treatment may have understood themselves to be performing responsibilities to their kin, but were cast in healthcare systems as lacking responsibility. The possibility that some patients might accept the biomedical risks of receiving treatment in remote areas in order to remain on country did

not appear to be canvassed in Northern Territory renal services. The governance of medical risk represented attempts to manage the behaviour of patients cast as dependent and lacking the agency to adhere to treatment. Yet the governance of risk displaced patients from the social relations that sustained their agency and provided a life worth adhering to treatment for.

The construct of medical risk could cast responsibilities in Northern Territory renal services in ways that could threaten the professional registration and professional standing of health professionals. One nurse working in primary healthcare and providing care to renal patients illustrated the potential ramifications of patient non-adherence to treatment for staff:

> (Remote dialysis) *puts them* (patients) *in a bad position and it puts us in a bad position… We can't force people to take their tablets, because that's their right of choice. The issue here and everywhere is when things go pear-shaped they expect medical staff to fix it, sometimes it's not possible if they're not compliant. It's on us because when it goes to a coroner's case… the poor old nurse is under extreme pressure.*

The deaths of renal patients in certain circumstances, including from complications of end stage kidney disease, could indeed be subject to coronial inquiries. This was the case in both Darwin and remote Indigenous communities. Coronial enquiries could threaten staff, even if staff were ultimately absolved of malpractice. The ways that conceptualisations of risk in remote Indigenous communities cast responsibilities and liabilities in Northern Territory renal services worked to legitimate the high levels of control over patients' bodies, lives and physical location exercised in healthcare systems. As this thesis has shown, and as Jeannie Devitt and Anthony McMasters also discuss, urban displacement could effectively constrain the lives of patients significantly (Devitt & McMasters 1998). As argued in previous chapters, paternalistic practices in healthcare systems, including urban displacement, could be a corollary of patient behaviour that did not conform to particular conceptualisations of patient responsibilities.

Patients seen to exercise positive responsibility could be cared for differently within renal services. The risk discourse that health professionals and policymakers engaged in did not represent a preoccupation with prolonging life at all costs, and those I interviewed were generally supportive of patients who decided to cease treatment, as an enactment of patient choice in which patients accepted responsibility for the outcomes. Maureen, a renal nurse, articulated the sentiments of other colleagues when describing supporting patients who refused or decided to cease dialysis treatment, telling me, 'my aim is quality of life… not longevity so much, and (my aim is also) the patient choice'. Northern Territory renal services assisted patients who had decided to cease treatment to return to their country and enter a palliative state, funding their transportation. Renal services' responsibilities

were constituted differently when patient deaths could be attributed to patient choices, irrespective of questions about the conditions of life in Darwin that may have prompted such a choice.

Contention over the expansion of dialysis services in remote Indigenous communities was animated by the responsibilities and liabilities that renal services in remote areas were seen to create in healthcare systems, in addition to their financial costs. Disputes over the risks and responsibilities of remote dialysis frequently played out in contention between the staff of primary healthcare services in remote communities and specialist renal services based in Darwin and Alice Springs. While renal service staff often described themselves as proponents of self care dialysis, performed by patients and their buddies in their communities, the staff of primary healthcare services expressed concern about the potential liability that patients returning to their communities posed. Remote primary healthcare staff were not generally trained in the specialty area of dialysis, usually categorised as tertiary healthcare. Although they were not responsible for administering dialysis to patients in remote communities, which was performed by visiting or resident renal nurses, or through self care patients' own labour and that of their buddies, they were tasked with providing emergency and preventative care to patients. Renal service policymakers related instances in which remote primary healthcare staff had registered their opposition to certain patients returning to their community and undertaking dialysis treatment there on the basis of patients' previous low adherence to treatment and the potential liability presented to staff. Through contention over the distribution of risk and responsibility, remote primary healthcare staff were known to have obstructed the construction of remote dialysis facilities and withheld permission for dialysis trucks to park on their premises. The construct of medical risk and the way in which it cast the responsibilities and liabilities of health professionals could reinforce disparate values and expectations of care between patients and staff, in addition to creating contention over the responsibilities of care within healthcare systems[36].

Through the construct of medical risk and the way it structures responsibilities and liabilities in renal services, patients are cast as vulnerable dependents who are unable to take responsibility for their own health. The value accorded to patient biomedical safety and the protection of staff from liability prevents Northern Territory renal services from acknowledging the interdependent relations between healthcare systems and Yolŋu families in sustaining patients' health. Key scholars of the anthropology of care have described healthcare as emerging from asymmetric but interdependent relations of care

[36] Medical risk and the way it cast responsibilities and liabilities could also impact on renal patients' access to accommodation in Darwin. I was informed by a renal services staff member that two NGOs tasked with providing accommodation to vulnerable people in Darwin were refusing to provide services to renal patients due to the potential liability that patients were seen to present to their organisations. They operated, respectively, a hostel that provided accommodation to Indigenous people from remote communities and a women's shelter.

between patients and health professionals, in which care and its effectiveness is shaped by patients' responses (Kleinman 2013; Mol 2008). I argue here that the professional liability of health professionals also emerges from asymmetric but interdependent relations of care between staff and patients. However, paradoxically, in Northern Territory renal services, efforts to promote patient biomedical safety and to protect staff from liability take the form of paternalistic measures that cast patients as dependents and that make them unwell through urban displacement.

An inability to recognise the value of interdependencies between families and healthcare systems

While place also figured prominently in Yolŋu narratives of health and disease, Yolŋu articulated a very different danger of end stage kidney disease: the existential threat of urban displacement. Yinin described the foreign, weaker *märr* that patients embodied through displacement. The weak *märr* of displaced patients led to them 'fading, drifting away… because they know, they know that their body is going to change later on. In two or three years' time they will change eventually. They will not be the same people'. As earlier chapters have shown, the displacement of patients from social roles and social geographies in remote communities could cause them to experience a loss of personal substance. As Ian Anderson (1995) has elucidated, medical risk constructs health and illness in a way that denies experiential dimensions of illness and the ways in which patients inhabit their own bodies.

Insufficient *märr* among patients displaced to Darwin could, for some patients, make one's life no longer worth living. As noted in earlier chapters, patients in Darwin who lacked carers were thought to be especially depleted of *märr*, leading some to take up drinking and miss or cease treatment. In remote communities, sets of relations within patients' social geographies that encompass kin, country and ancestors may provide a life worth adhering to treatment for. This point was devastatingly demonstrated by the patient excluded from the Galiwin'ku pilot due to concerns about risks to her health. Around six months later when the woman, in her 40s, was informed by health professionals that she would need to move from her public housing abode in the Darwin suburbs to an aged care facility, she took her own life. The existential threat of urban displacement described by patients was undeniable.

The displacement of renal patients to Darwin could also pose broader threats to Yolŋu society. Mr Muŋul̲purr lamented the destructive impacts of displacement to me:

> *When we get this sickness we feel like we nobody. That's how we feel. Like we bin let down. We lose everything. We lose family, we lose the good time, we lose friends, we lose future. That's what this sickness does… I look at myself, I say I was not like this before. I was huge big man. I used to work for community police for four years. I used to go hunting every day, on the weekend fishing, spearing, but this sickness bin slow me down. I used to be a tribal leader for the Djambarrpuyŋu clan, I used to lead them but not anymore, because this sickness shut down my future. Shut down the main transfer.*

Displacement could dispossess Yolŋu society of knowledge and leadership, as well as patients of social status. As noted in the Introduction, Yolŋu were not generally dispossessed of their country in earlier eras of colonisation. The way in which they received healthcare, however, represented a contemporary form of dispossession. While previous chapters have shown that Yolŋu domestic moral economies could be reconfigured in new ways in Darwin, ultimately, the realisation of social value in Yolŋu families required dialysis treatment to be made available on country.

Universally, Yolŋu renal patients and their families articulated desires for nurse-assisted dialysis to be made available in remote areas on a permanent basis. Yolŋu tended to articulate claims for dialysis to be made available in their communities, not necessarily as an entitlement, but as enabling the performance of other responsibilities within their own interdependent networks of care and relationality. Mr Muŋuḻpurr explained, 'our ancestors' spirits, they need us back. Our country, our children will grow strong, grow healthy because of us. We'll feel them when we go there. We've gotta teach them'. Yiŋiya Guyula was an independent Yolŋu Member of the Northern Territory Parliament who had been campaigning for better access to renal services in his north east Arnhem Land electorate. Yiŋiya described the grounds for remote dialysis similarly:

> *I want to encourage all patients, people and even Health Department to support in just, supporting in these machines, dialysis machines back onto country, that's why they can live on fresh food. Like I said, fresh food plus keeping an eye out onto their children, there's lots of children that are going just undisciplined so they start breaking in, they do all sorts of things, especially when young parents are there, they are unexperienced young parents, they don't know what to do. That's where they need their grandparents but unfortunately they are stuck in here* (Darwin)*. Yes, education and more knowledge, passing on the knowledge, language, teaching language, we are losing so many senior elders from communities, homelands.*

Yiŋiya was lobbying the Northern Territory Government to make dialysis available in homelands. His comments implied a need for responsibilities of care in Yolŋu families and communities to be recognised in policy frameworks.

The threats that urban dialysis and displacement posed to Yolŋu were well known to health professionals and policymakers, but remained illegible to healthcare systems that placed value on

biomedical safety and reducing staff liability. The ramifications of urban displacement for the health and lives of Indigenous patients from remote areas have been subject to decades of research and advocacy (eg: Cass, A, Feyer, et al. 2011; Devitt & McMasters 1998; Hoy 1998; Hughes, J et al. 2018; Lowe et al. 1995; Willis 1995). However, the construct of medical risk did not encompass the existential threat that urban displacement posed to patients, and healthcare systems declined to accept responsibility for the impact of displacement on patients' lives. In Northern Territory renal services, the inability to recognise the potential value of interdependencies between Yolŋu families and healthcare systems in sustaining patients through remote dialysis prevents the realisation of health policy agendas of improving patient health and adherence to treatment. Such outcomes would reduce some forms of medical risk and the professional liability of staff. The ways that Northern Territory renal services cast patients as dependents and fail to recognise interdependent relations between healthcare systems and families in caring for patients also poses existential threats to Yolŋu.

Northern Territory renal services also fail to realise financial benefits of the interdependent relations between healthcare systems and Yolŋu families in caring for patients. Urban models of dialysis, which afford patients insufficient care and present an existential threat to patients, also provide inadequate treatment. As discussed in the Introduction, Northern Territory renal services have been slow to respond to rapidly increasing numbers of patients in Darwin, who have overwhelmed urban renal wards and units. Renal services in Darwin operate beyond capacity, relying on patient non-attendance and a policy of deferred treatment. While some Yolŋu leaders such as Yiŋiya were campaigning for public funding for renal services in remote communities, remote services in the Northern Territory, including the Galiwin'ku pilot, have often been funded at least partially by communities themselves and through philanthropic donations. Remote dialysis services in fact relieve pressure on severely strained urban facilities and on their budgets through interdependencies in values and objectives of care between renal services and Yolŋu.

Conclusions

In Chapter Three I described the care for Yolŋu renal patients in Yolŋu domestic moral economies, and how Yolŋu families have attempted to maintain care for renal patients and realise social value in new ways following displacement to Darwin. In Chapter Four, Five and Six, I described the disparate values and practices of care enacted in Yolŋu families and in Darwin renal services and through social policy. In this chapter I have continued to explore how social value, relations of care and processes of personhood among Yolŋu are compromised, ultimately, by health policy that offers treatment through

urban displacement. In Yolŋu domestic moral economies, in which caring for others can make one who one is, the inability to do so could present an existential threat. I have argued that for Yolŋu, realising social value and maintaining relations of care between people, country and ancestors ultimately requires access to dialysis on country.

In Darwin renal services, discourses of medical risk could transform health professionals and policymakers' compassion for patients and concern about the structural inequalities in their lives into paternalistic, illiberal responses. Medical risk was operationalized in renal services through the concept of duty of care, in ways that recast contention over the distribution of healthcare geographically and amongst patients, and the responsibilities of healthcare systems, into questions of safety and liability. The governance of medical risk in ways that dictated where patients received treatment recalled health professionals' conceptualisations of care as a gift creating social debt and dependency amongst patients and legitimating paternalistic practices, as discussed in Chapter Four; and similar conceptualisations of care as a gift provided to those deemed legitimately dependent in social security policy discussed in Chapter Six. Medical risk gains particular salience in neoliberal times in which access to healthcare is less universal, working to determine the distribution of scarce dialysis chairs in remote Indigenous communities. While the new funding arrangements for remote dialysis discussed in the Introduction are likely to see more nurse-assisted dialysis services established in remote Indigenous communities in future, concerns about medical risk of continue to prevent some patients from accessing treatment in their communities.

In previous chapters I have argued that through disparate values and interdependent relations of care between Yolŋu and the state, in which patients are cast as state dependents, the state mobilises yet marginalises Yolŋu relations and practices of care. Here, I have argued that dialysis on country, in tandem with the sets of social relations in patients' communities, enables the realisation of interdependent values and objectives of care among Yolŋu and Northern Territory renal services. Remote dialysis services allow Yolŋu patients to realise better social and embodied health and provide capacity for families to realise social value. Remote dialysis services also allow healthcare systems to realise improvements to key biomedical metrics of patient health and in some cases, financial savings. Northern Territory renal services and Yolŋu families require one another to realise interdependent values and objectives of care. In Northern Territory renal services, in which patients are cast as dependents, the failure to recognise the potential value of interdependent relations between families and healthcare systems in sustaining patients prevents the realisation of health policy agendas and poses existential threats to Yolŋu. While the interdependent relations of care between Yolŋu and the state may thus function in exploitative ways in some circumstances, as Chapters Four, Five and Six

showed, this chapter has revealed that health service delivery models that fail to support Yolŋu relations of care can produce negative consequences for both Yolŋu and the state. In the following chapter I will explore funding proposals advanced by Yolŋu organisations for renal services in north east Arnhem Land communities, and how interdependent relations between Yolŋu and the state may provide an avenue for Yolŋu to realise social value in some circumstances.

Chapter 8

Bala-räli (two-way exchange): Towards a care-ful sovereignty

When the anthropologist Donald Thomson conducted fieldwork with Yolŋu in the 1930s, towards the end of a period of frontier violence, he described his offering of basic treatment for the ailments of his interlocutors as helping to establish hospitable relations (Thomson 1983: 7). Several generations on, some Yolŋu continue to speak fondly of Donald Thomson, and one of my interlocutors proudly informed me that her forbears had worked with him. In contemporary times, healthcare for Indigenous people continues to take on a particular moral valence as reparation for past dispossession and trauma. Closing the Gap, the dominant meta-narrative of Indigenous health policy, was launched in 2008 by then-Prime Minister Kevin Rudd, in tandem with his official apology to the stolen generations – Indigenous children who were involuntarily removed from their kin and relocated into missions, state institutions and adoptive white families in attempts to assimilate them into white lifeworlds. The Closing the Gap framework aims to eliminate statistical disparities between Indigenous and non-Indigenous Australians across a range of health and other indicators (Council of Australian Governments & Coalition of Aboriginal and Torres Strait Islander Peak Organisations 2020). Rudd described the framework as inaugurating 'a future based on mutual respect, mutual resolve and mutual responsibility' (Rudd 2008). The idea that healthcare can make amends for colonisation, as a gift that assuages a deep historic debt, is a recurring narrative. Through Closing the Gap, healthcare is positioned as integral to the state's responsibility to Indigenous Australians.

In this chapter, I consider how care is integral to the shifting relationship between Indigenous people and states. Feminist theorists have placed care in the domain of politics and relationships between people and states, arguing that domestic labour comprises an essential but unrecognised element of social contracts between citizens and states in liberal societies (Sevenhuijsen 1998; Thelen 2015; Tronto 1993). Moreover, healthcare, which I have shown to be constituted through relationships of care between health professionals and patients, is typically considered an essential component of

states' responsibilities to citizens in liberal states. Here, I consider care as an interdependent relation between Indigenous people and states. I illustrate how Yolŋu have sought to remake relations with the Australian state and broader Australian society through healthcare, and through concepts of exchange, reciprocity, interdependency and care. I discuss the Yolŋu concept of *bala-räli*, 'two ways' or 'exchange', which describes a relation of partnership, co-contribution and care between peoples and collectivities, in order to develop a concept of a public ethics of care, beyond the feminisation and romanticisation of care and beyond its typical confinement to a domestic sphere. I consider the implications of the relations of interdependency and care between Yolŋu and the state.

In previous chapters I argued that for Yolŋu, realising social value requires renal services to be made available in their communities. Both a lack of public funding and concerns about medical risk have prevented some Yolŋu patients from receiving dialysis treatment in their communities. The funding for dialysis services in north east Arnhem Land is the central topic of this chapter. I examine funding proposals that Yolŋu have advanced for renal services in their communities, which embody the values and ideas of *bala-räli*. I show how Yolŋu proposals for co-contributions to dialysis services by Indigenous organisations and governments do not simply represent a response to neoliberal conditions or complicity in responsibilisation agendas, and are interwoven with broader ambitions for the recognition of the sovereignty of Yolŋu nations within the Australian state. While previous chapters have examined contending values of care within health and social policy and Yolŋu domestic moral economies, here I consider the possibility of confluence of values between Yolŋu and government health agendas in a public, political domain. I argue that a public ethics of care is integral to both healthcare for Yolŋu and Yolŋu sovereignty claims.

Locating Indigenous sovereignty within states

The anthropology of states and studies of governmentality have unsettled classic understandings of sovereignty as the supreme control of states over bounded territories (Roitman 2005; Trouillot 2001). In federal systems of governance and in the presence of international governance bodies, the notion of sovereignty as supreme and independent power is difficult to sustain. Scholars of the state have directed analytic attention to the modes of governance and power that operate at the margins of states (Asad 2004). Constructs of state sovereignty as incomplete and contingent open up avenues for understanding Indigenous sovereignty within settler states as co-existing or overlapping with the sovereignty of states.

Danilyn Rutherford (2012) conceptualises sovereignty as a process of recognition of nationhood. Paradoxically, sovereign nationhood is a status that relies on other nations, institutions and peoples for its validation. The interdependent nature of sovereignty, understood as a process of recognition, provides avenues for subaltern groups to claim power. Through ethnographic work in West Papua, Rutherford argues that audiences are integral to sovereignty claims. Here I argue that Yolŋu are highly sensitised to the reliance of their sovereignty and healthcare claims on relationality and recognition, and on audiences and performances.

Jessica Cattelino (2008), in her relational theory of sovereignty, calls for a broadening of our conceptualisations of sovereignty beyond a legal status. Based on ethnographic work with Seminole in North America, who operate casinos and who donate to governments and contribute to community projects, Cattelino argues that Indigenous sovereignty is also a practice, a relation and a mode of subjectivity. Seminole sovereignty is enacted through interdependent relations between peoples and sovereigns, and practices of reciprocity and recognition. Cattelino locates the possibilities for Indigenous sovereignty not at the state's margins but as implicated in state sovereignty. Cattelino sets aside the opposition often held to exist between autonomy and dependency in conceptualisations of sovereignty, and this parallels the opposition frequently constructed between autonomy and dependency in care scholarship, as noted in the Introduction. Following Cattelino, I move beyond both oppositions to argue that Yolŋu claims for healthcare and for sovereignty are both premised on interdependencies existing within unequal relations between Yolŋu nations and the Australian state. I explore how the interdependencies of care shape the relationship between Yolŋu and the state

I commence by exploring Yolŋu conceptualisations of the causes of end stage kidney disease that connect poor biomedical health status to the lack of recognition of Yolŋu political structures, customary law and hunter-gatherer economies within the Australian state. I go on to discuss the concept of *bala-räli,* a public ethics of care*,* and how Yolŋu mobilise it in their relations with the state and street level bureaucrats. I examine a series of funding proposals for dialysis services in north east Arnhem Land initiated by Yolŋu and their supporters and then discuss how Yolŋu draw on interdependencies of a material and political nature to make claims for dialysis services. Finally, I discuss the implications for our understandings of care, health policy and Indigenous sovereignty.

A disease of colonial relations

A slow, heavy ambience seemed to fill the room one humid wet season morning as I sat in the Parliament House office of Yingiya Guyula MLA. Yingiya sighed and gazed out the window, as he explained to me the causes of the preponderance of end stage kidney disease amongst Yolŋu:

> *But I think this is what's causing it, it's people living in hub communities[37] and just going to the shop. People living in hub communities are all clans all around, different clans, there's fear and there's conflict. Going out hunting, people mightn't go beyond this point over here because it belongs to another clan over here. When they're back on their own country they're free to go anywhere they want.*

I had heard Yingiya make similar statements many times before. He had often pinpointed the causes of chronic disease and social malaise in Yolŋu communities to the settlement of Yolŋu on missions that later became small towns. The centralisation and sedentarisation of multiple clans into towns, established on the country of one particular clan, according to Yingiya, led to the subsequent curtailing of hunter-gatherer economies to some extent, as Yolŋu were reluctant to hunt and gather on the country of other clans.

Like Yingiya, Yolŋu with end stage kidney disease tended to attribute the emergence of chronic disease to colonisation and associated changes in production and consumption. Helen recalled that in her youth, 'old people didn't get sick – no sugar'. She explained that for those who didn't live on missions, the only sweet food available was wild honey, which had a brief seasonal availability, and elaborated, 'that's why all the old people were really strong by bush tucker'. Wapiriny recalled living on rations of flour, sugar and tea provided at missions in his youth, and held missionaries responsible for failing to educate Yolŋu about Western foods. Others blamed the introduction of commodified Western foods after missions were dismantled in the 1970s, particularly soft drink, lollies and bread, for the epidemic of chronic disease.

These perspectives of the causes of end stage kidney disease echoed the Yolŋu conceptualisations of health discussed in Chapter Two, as produced by the quality of one's relationships with kin and country and as requiring mobility. They also reflected, to some extent, biomedical theories that link the epidemic of end stage kidney disease amongst Indigenous Australians to lifelong nutrition, amongst other factors (Cass, A et al. 2004). Yolŋu interlocutors, however, went further in attributing

[37] 'Hub communities' are another example of 'hub and spoke' service delivery models. 'Hub communities' are major remote Indigenous communities designated by the Commonwealth and Northern Territory Governments for greater levels of investment in infrastructure and services. Investment in hub communities has been accompanied by a withdrawal of financial support for homelands.

their kidney disease to the ongoing lack of recognition of Yolŋu clans and law by the Australian state. Dianne, for example, explained to me,

> *They* (health professionals) *are blind to look for it. Everything about Yolŋu is not acknowledged – skills, food, rom* (law). *They don't know because of the dominant culture taking over everything, leaving us one way, Balanda order. Then they forget about our order, food everyday, all the wellbeing, depend on the Balanda world. Dependency is gonna kill you because you're cutting short the ability to do things for yourself.*

Dianne described the lethality of the present relationship between Yolŋu and health professionals, as the proxy of the state, in which the denial of Yolŋu law was continuous with economic changes and the transition to Western diets. Dianne's perspective on the dependency of Yolŋu on the state recalled the unease expressed by other Yolŋu interlocutors about dependency in the absence of relationality, as discussed in earlier chapters. Dianne's comments also suggest that the realisation of the value invested in Yolŋu skills, food and law requires recognition in a 'Balanda order'. I argue that Dianne's concern about dependency did not necessarily express a desire for separatism. The Yolŋu leader, Dr Galarrwuy Yunupiŋu[38], who has publicly discussed his experiences of end stage kidney disease (see Lawton 2018), has also argued that Yolŋu law is only effective if recognised by the Australian state (Yunupingu 2008). Yolŋu have often described their cultural alterity and autonomy as requiring not separatism but recognition within the institutions of the state (Fisher 2016). Yolŋu have a deep appreciation for the terms of their recognition by the state to shape their everyday lives and health.

Based on conceptualisations of health as a physical and social state, and perspectives of kidney disease as a disease of colonial relations, Yolŋu have sought remedy by asserting claims for recognition of their care needs and of their nationhood in the Australian state. As the following sections will show, themes of sovereignty, recognition and interdependency have featured strongly in various attempts to secure renal services in north east Arnhem Land; and claims for remote renal services could converge with wider political objectives of achieving the recognition of Yolŋu clan-nations as nations existing within the Australian state.

Bala-räli (two-way exchange): advancing a relational mode of sovereignty

Through the idiom of *bala-räli,* Yolŋu counter colonial relations and express claims to a relational mode of sovereignty. In Chapter Three, we encountered *bala-räli,* meaning 'towards and away', 'two

[38] Dr Galarrwuy Yunupiŋu was awarded an honorary Doctor of Laws by the University of Melbourne.

directions' or 'exchange', as a relation of care and reciprocal exchange between Yolŋu collectivities. Generalised forms of reciprocity within family groups and between health professionals and patients have been my focus in Chapters Three to Six. In this chapter, however, I attend to the practices of balanced exchange and relations of formal political equality held to exist among Yolŋu clans expressed by *bala-räli.* Yolŋu claims for recognition of sovereignty within the Australian state have repeatedly instrumentalised the idiom of *bala-räli*. The term *bala-räli*, or 'two ways', as it is also known, recalls Yolŋu expressions of personal agency and the extending of one's personal networks as the making of 'pathways', as discussed in Chapter Two. As Frances and Howard Morphy describe, through the idiom of 'two ways', Yolŋu express the equivalence and compatibility of Yolŋu and Western knowledge. 'Two ways' expresses a cosmopolitan desire among Yolŋu to share and to participate in cultural and economic exchange within broader Australian society, without compromising their beliefs and values (Morphy, F & Morphy, H 2013; Morphy, H 2016).

As in classic gift theory, Yolŋu practices of balanced exchange sustain relationships among people and collectivities (Mauss 1954). Some practices of balanced exchange in other societies, particularly in Melanesia, have been described as practices of 'agonistic gifting' (Graeber 2001), as aggressive forms of exchange in which gifts create a social debt until a return is made, and which may be deployed to enhance the status of the giver. In the form of balanced exchange practiced by Yolŋu through *bala-räli*, however, gifts are given in attempts to compel receivers to recognise their relationship and responsibilities to the giver. *Bala-räli* may be understood as a process of co-contribution as well as exchange. Yolŋu clan leaders who have acquired substantial power or resources are careful to describe the limits to their authority as one clan leader among many, and to respect the formal political equality of clans (for example, Yunupingu 2008).

Bala-räli emerges from Yolŋu cosmologies underlined by partnership and balance. Yolŋu social universes are divided into Dhuwa and Yirritja moieties, including people, clans, country, elements, objects, animals and plants (Marika et al. 1992; Thomson 1949). Dhuwa and Yirritja exist as inseparable opposites, for example, between husbands and wives, in clan alliances and in adjacent parcels of land; and their dualism is often represented in Yolŋu art and ceremonial performance (Marika et al. 1992; Thomson 1949; Williams, N 1986). In funeral ceremonies I attended, participating Dhuwa and Yirritja clans each contributed their dances and songs to the performance. Based on his fieldwork conducted in the 1930s and 1940s, Donald Thomson described ceremonial exchange among Yolŋu clans, in which value inhered not primarily in the objects exchanged, but in the performance of the ritual (Thomson 1949). Thomson described ceremonial exchange as imbued with *märr,* suggesting that the value produced by ceremonial exchange can also be understood to

exist in the reproduction of relationships amongst participants and clans. Through Dhuwa and Yirritja moieties and relationships among clans, relationality, interdependency and interlocking responsibilities form the architecture of Yolŋu cosmologies.

Through the Dhuwa/Yirritja cosmology and the idiom of exchange, Yolŋu have incorporated foreign people and objects into Yolŋu lifeworlds. Prior to colonisation, Yolŋu traded with Makassan seafarers from what is now the Indonesian island of Sulawesi, from at least c1700, and possibly for 1000 years (Clark & May 2013). Makassans harvested *trepang* (sea cucumber; *bêche-de-mer*) in coastal areas of north east Arnhem Land, aided by Yolŋu labour, in exchange for the food, tobacco, cloth, alcohol, axes and knives they bestowed on Yolŋu owners of sea country. Some Yolŋu men also travelled to what was then known as Makassar (now Ujung Pandang) and married Makassan women (Clark & May 2013; Macknight 1976). Makassans and the material objects that they introduced have become incorporated into Yolŋu lexicography, into Yirritja ritual and secular lifeworlds, including *galiku'* (calico), *ŋarali'* (tobacco), *bandirra'* (flags), *rrupiya* (money), *lipalipa* (dugout canoes) and *berratha* (rice) (Berndt 1962; Magowan 2001a; Warner 1937). Campbell MacKnight (1976) notes that Makassans did not compete with Yolŋu for resources nor seek to impose religion, in comparison to subsequent British colonists. Although trade with Makassans was banned by colonial authorities in the early 20th Century, in contemporary times Yolŋu continue to valorise their historic exchange relations with Makassans beyond a purely economic relationship, as productive of mutual respect (Pera Tane & Harwood 2017).

Yolŋu express desires for mutual respect for cultural difference, the formal political equality and exchange through *bala-räli.* Yolŋu leaders described their embracing of Christianity while maintaining Yolŋu spiritual beliefs, and the incorporation of a Christian God as *waŋarr* (an ancestral being), as exemplifying a 'both ways' or 'two ways' stance in the 1960s (Morphy 1991, Morphy 2005). Since the 1970s, the bilingual curriculum at the Yirrkala school developed by Yolŋu educators has been described as 'two-way learning' (Marika-Mununggiritj and Christie 1995, Marika 1999, Corn 2009). Yolŋu have also described themselves as engaged in 'two-way research' (Marika, Ngurruwutthun et al. 1992, Colles and Maypilama 2014) and 'two-way ranger programs' (Marika, Yunupingu et al. 2009). The late Yolŋu scholar and educator Dr R Marika described Yolŋu philosophies of *ganma* and *milŋurr*, as exemplifying the Dhuwa/Yirritja cosmology, and their relation to 'two-way learning':

> *Ganma is firstly a place; it is an area within the mangroves where the salt water coming in from the sea meets the stream of fresh water coming down from the land. Ganma is a still lagoon. The water circulates silently underneath, and there are lines of foam circulating across the surface. The swelling and retreating of the tides and the wet season floods can*

> *be seen in the two bodies of the water. Water is often taken to represent knowledge in Yolŋu philosophy. What we see happening in the school is a process of knowledge production where we have two different cultures, Balanda and Yolŋu, working together. Both cultures need to be presented in a way where each one is preserved and respected. This theory is Yirritja.*
>
> *I will now talk about milŋurr, which is Dhuwa, the opposite theory. Milŋurr is a name of sacred spring water. It is created by the mawalan, the walking sticks of the Djaŋ'kawu ancestral being— my ancestor. This is a metaphor that my father used to help me to understand about teaching and learning. Milŋurr represents the ebb and flow of water. We use this to represent the way we learn. When the tide is high, we are full of new knowledge, new ideas, new thinking. When it ebbs, we are looking for new things* (Marika 1999: 7).

Bala-räli, or 'two ways', may be seen to operate within a public Yolŋu ethics of care and responsibility, both describing and enacting relationships between people and collectivities.

Yolŋu desires for the sovereignty of Yolŋu clans within the Australian state underlie *bala-räli*. As noted in the Introduction, Yolŋu sovereignty claims emerge from particular colonial histories in which the status of Yolŋu within the Australian state for long remained unsettled and through which Yolŋu were not generally alienated from their country. State incursions into clan authority through the subjection of Yolŋu to Australian law, the establishment of missions and mineral exploration historically brought to a head the overlapping sovereignty of Yolŋu and the state. Mining on the Gove Peninsula also led to the Milirrpum v Nabalco Pty Ltd case of 1971, the first time that native title was litigated in Australia, and eventually, the recognition of Yolŋu land ownership in Australian law through the Aboriginal Land Rights Act 1976 (Williams, N 1986). According to Dr Galarrwuy Yunupiŋu (2008), Yolŋu law is only effective if recognised by the Australian state. Yolŋu sovereignty claims represent desires for the recognition of Yolŋu law within Australian law and for political and economic autonomy in north east Arnhem Land but not independence. The Constitution of the Yolŋu Nations Assembly describes its major objectives as achieving recognition of Yolŋu clans as nations within the Australian state, establishing diplomatic relations with the state and instituting a system of Yolŋu governance compatible with Westminster parliamentary democracy (Yolŋu Nations Aboriginal Corporation 2018). The Yothu Yindi Foundation articulates desires for Yolŋu to exercise greater decision-making power over the use of government funds at a regional level through Yolŋu political structures (Yothu Yindi Foundation 2017b). *Bala-räli*, I argue, expresses Yolŋu desires for formal political equality among polities, including among clans, and between clans and the state.

Yolŋu clan leaders often appear to imagine themselves to be representing clan-nations in dialogue with the state and broader Australian society. Although clan leaders have often been strident critics of government policy, the public pronouncements of Yolŋu clan leaders often have a diplomatic

quality. In late 2017, great diplomacy was in evidence when a plane carrying the body of a deceased Yolŋu man, related to some of my interlocutors, crashed during its journey from the morgue in Darwin to Galiwin'ku for the funeral. The crash was found to have been caused by the violation of operating procedures by the two pilots, who flew through a storm. The two pilots, who were young non-Indigenous men stationed at Galiwin'ku, were fatally injured in the crash, and the already-deceased man's body was dismembered. The deceased's uncle expressed condolence to the pilots' families, magnanimously describing them as members of the community at Galiwin'ku (Breen 2017). Yolŋu valorise clan leader 'heroes' of the 20th Century who adopted a diplomatic stance, despite the destruction wrought on clans by the violence of early colonialism and subsequent development. Wonggu, for example, was dubbed 'the peacemaker' following a period of frontier violence, and Mungarrawuy Yunupiŋu the 'great conciliator' in his attempts to negotiate with the operators of the bauxite mine at Nhulunbuy (Morphy, H 2005). Through the diplomatic gestures of clan leaders, Yolŋu perform their sovereignty claims as a relationship between groups of people.

Yolŋu desires to remedy illness through the recognition of Yolŋu sovereignty within the state express a divergent objective to the 'Closing the Gap' framework of Indigenous health policy, of statistical biomedical equality. Some Yolŋu, however, have sought to mobilise the 'Closing the Gap' meta-narrative, that healthcare can make amends for colonisation. Some, including Yinin, sought to redefine 'Closing the Gap' as narrowing fissures in mutual understanding, particularly in healthcare contexts. Jeffrey, while acknowledging that the policy framework referenced the poor biomedical health of Indigenous people, saw political equality as the missing ingredient that had prevented efforts to improve health from succeeding. He commented to me, 'all blackfellas say the same. Treaty – that is the answer. That's how we'll close the gap'. Both Yinin and Jeffrey's perspectives on 'Closing the Gap' positioned the framework as requiring recognition and partnership.

While *bala-räli* references Yolŋu claims of sovereignty within the Australian state, it plays out through interpersonal relationships between Yolŋu and street level bureaucrats. For Yolŋu, realising *bala-räli* necessitates establishing relationships of mutual understanding with the usually non-Indigenous doctors, nurses, teachers and other street level bureaucrats tasked with providing services to them. As previous chapters have explored, such relationships were not generally subject to balanced exchanges of labour or exchanges of a material nature. *Bala-räli*, when invoked by Yolŋu in relation to their relationships with agents of the state, could express desires for cultural exchange, or exchanges of knowledge and understanding. Recognition and respect were only possible through relationality, as Cattelino (2008) argues, and interlocutors often expressed desires for health

professionals to learn to speak Yolŋu matha and spend time with patients in order to understand their lifeworlds. Dianne, for instance, thought that:

> *There should be a program for Balanda to learn about Yolŋu if they're bringing them in* (to Darwin) *and how to engage properly. Because we are not coming from a Balanda world we are coming from a Yolŋu world. We have manners, respect, bala-räli - respect both ways. We have to learn everything to engage in your world, it's very hard for us. We have been forced to learn that. Some* (Balanda) *people just don't want to learn because they don't want to be forced, they happy where they are. But we have to learn because there are lots of diseases today… Making us follow another path all the time makes you sick, it's tiring, it disempowers you, that's part of the wellbeing.*

In Chapter Two, I argued that Yolŋu conceptualise their physical health as sustained by social relations. Here, Dianne argues that an absence of *bala-räli*, or relationships of mutual respect, forces Yolŋu to follow another 'path', recalling the forging of one's own pathways as an expression of positive agency. Dianne suggests that an absence of *bala-räli* restricts Yolŋu autonomy and makes Yolŋu sick. Dianne also associated an absence of *bala-räli* in renal units with a refusal to respect blood taboos through the separation of male and female patients. She complained that transgression of blood taboos in dialysis chair arrangements made her feel unwell. Ensuring Yolŋu renal patients felt cared for evidently required health professionals and healthcare systems to recognise Yolŋu *rom* (law, rules, norms). As we saw in the previous chapter, there was far greater scope for the realisation of this kind of *bala-räli* through relationships in remote dialysis services, in which power is enacted by patients and health professionals in different ways, compared to treatment provided in Darwin. Notably, during the Galiwin'ku pilot, efforts were made by nurses to provide treatment to male and female patients on different shifts. The realisation of *bala-räli* requires Yolŋu to be highly implicated in the state and to exercise particular responsibilities, for example, by holding roles as Indigenous Health Workers, teachers' assistants and interpreters. The realisation of *bala-räli* may also underlie the desires expressed by interlocutors for Yolŋu to be employed in renal services discussed in Chapter Four.

Bala-räli is both normative, expressing an imagined future place for Yolŋu collectivities within the Australian state, and transformative, creating and shaping the terms of their recognition. *Bala-räli* functions both as an expression of value in cultural alterity, sovereignty, partnership and care; and as a discursive resource for their realisation. Although the formal recognition of Yolŋu clans as nations within the Australian state remains elusive, the idiom of *bala-räli* could be compelling to Balanda street level bureaucrats, enabling them to position themselves as engaged in respectful partnerships. As discussed in Chapter Four, health professionals caring for renal patients often expressed sensitivity and respect for patients' cultural alterity, and in doing so embodied institutionalised norms of cultural security. Concurrently, health professionals expressed substantial discomfort with the dependency of

patients on their caring labour, which often went well beyond the provision of biomedicine. For health professionals, patient dependency could be equated with the reproduction of colonial relations. *Bala-räli* provides a welcome discursive frame through which many Balanda health professionals, teachers, researchers, community development workers and others have positioned themselves as engaged in respectful partnerships with Yolŋu and other Indigenous people (see for example Colles & Maypilama 2014; Laycock et al. 2011; Marika et al. 2009; Nagel et al. 2009). The causes Yolŋu attributed to kidney disease, and the responses they sought to enact, offer a rebuke to Emma Kowal's provocation, that the 'overstructuralisation' of Indigenous peoples' health works to deny Indigenous agency (Kowal 2015). The language of equality and mutual respect offered health professionals and other street level bureaucrats legitimacy, allowing them to position themselves as engaged in a non-colonising practice.

In previous chapters, I have argued that government policy agendas are parasitic on Yolŋu practices of reciprocity and care; here, I suggest that state actors also deploy Yolŋu concepts of exchange and care discursively. Nevertheless, bureaucrats who described themselves as involved in a 'two-way' practice appeared to be seen by my Yolŋu interlocutors as representing a Yolŋu discursive and political achievement. *Bala-räli* offered a mechanism for achieving recognition by and relationality with agents of the state. As Rutherford (2012) suggests, recognition can thus be understood to operate in a Hegelian fashion, as an interdependent relationship between unequal parties. Through the instrumentalisation of *bala-räli*, as a practice and as a discursive resource, Yolŋu have attempted to make governments more accountable for fulfilling their care needs.

Mobilising the values of *bala-räli* in funding proposals for renal services

Through funding proposals for renal services in their communities, Yolŋu have responded to end stage kidney disease, understood as a disease of colonial relations, and the existential threat presented by urban displacement. Funding proposals over the past two decades have often exemplified the forms of value expressed by *bala-räli,* of partnership, mutual respect and balanced exchange or co-contribution. Through funding proposals, Yolŋu have attempted to compel governments to take responsibility for renal services in north east Arnhem Land. In the following, I trace the emergence of Yolŋu proposals for co-contributions by Yolŋu organisations and governments to renal services in their communities.

Mobilising the social capital of *bala-räli* to establish the Yirrkala Renal Unit

A public campaign to establish renal services at Yirrkala was led by the Yolŋu musician, leader and educator Dr M Yunupiŋu[39] following his diagnosis with end stage kidney disease in the mid 2000s. Dr M Yunupiŋu was a former principal of the Yirrkala school and the founder of its two-way learning program, as well as the frontman of the internationally acclaimed Yolŋu band *Yothu Yindi*. The band's name referenced the relationship between its members and the clans with which they associated. According to Aaron Corn, the band's ethnographer, the concept of *Yothu Yindi* 'invokes social balance, equality and interdependence between bodies of people, Yirritja and Dhuwa' (Corn 2009: 9). In the early 1990s, the *Yothu Yindi* hit *Treaty* popularised recognition of Indigenous sovereignty. For his contribution to reconciliation, Dr M Yunupiŋu was awarded Australian of the Year in 1993 (Corn 2009).

The campaign for the Yirrkala Renal Unit drew substantially on the enormous social capital that Dr M Yunupiŋu had accumulated in broader Australian society through his fame, social networks and contribution to reconciliation, and the values of *bala-räli* that he had come to represent. The campaign also drew on in his social capital within Yolŋu society. In 2009, in a feature documentary on the current affairs program *Australian Story*, Dr M Yunupiŋu and his supporters described his personal struggles with the disease and with life in Darwin (Cheshire 2009). In the documentary, Dr M Yunupiŋu discussed descending into despondency and considering ceasing treatment, but regaining hope and purpose through imperatives to educate other Yolŋu about kidney disease. In 2012, *Yothu Yindi* released a new album, *Healing Stone*, featuring a title track that referenced Dr M Yunupiŋu's diagnosis and in its film clip featured footage of him receiving dialysis and Yolŋu medicine provided by kin (Yothu Yindi 2012). *Healing Stone* drew on themes of dualism and balance between Yolŋu and Balanda medicine, as well as interdependencies of care in Yolŋu families. The album represented Dr M Yunupiŋu's performance of efforts to improve awareness of kidney disease among Yolŋu and to contribute to disease prevention, while the film clip also featured the performance of Dr M Yunupiŋu's family's care for him.

The investment of Dr M Yunupiŋu's social capital was ultimately successful in compelling government funding for the physical and human capital required to run a renal unit. Later in 2012, Miwatj Health received funds from the Commonwealth and Northern Territory Governments to open the Yirrkala renal unit. The two-chair facility, offering nurse-assisted dialysis, was the first of its kind in the region. Miwatj Health publicly attributed its success to Dr M Yunupiŋu's status and efforts (Brooks 2015). In this case, the contributions of Dr M Yunupiŋu and the values that he represented succeeded in

[39] Dr M Yunupiŋu was awarded an honorary doctorate by Queensland University of Technology.

responsibilising two governments who had previously sought to responsibilise one another for remote dialysis services. As Michael Christie and John Greatorex (2004) argue, Yolŋu social capital, understood as norms, networks and trust, acquires power through its local specificity. However, Yolŋu social capital also has the potential to accumulate further value in public and political domains in broader Australian society.

Enacting *bala-räli* through financial capital in proposals to extend renal services

As the Yirrkala Renal Unit commenced providing treatment to Dr M Yunupiŋu and a small number of subsequent patients from Yirrkala and its surrounding homelands, questions remained as to how nurse-assisted renal services could be extended to other north east Arnhem Land communities. One Miwatj Health staff member expressed his frustration with a lack of further government funding following the deaths of Dr M Yunupiŋu and his nephew Dr G Yunupiŋu[40], also from end stage kidney disease, who had also been a member of *Yothu Yindi* and in his subsequent solo career had become Australia's highest earning Indigenous artist. He quipped, 'how many more Dr Yunupiŋus have to die for it to happen?'

Some of my Yolŋu interlocutors described the unequal access to dialysis in remote communities across the Northern Territory as an injustice. One commented wryly that the Tiwi Islands, where the Northern Territory Government operated the Tiwi Dialysis Centre, were the 'favourite place' of Northern Territory Government officials. He added, 'to me both governments should help. I'm a taxpayer. I'm a citizen'. Wapiriny similarly questioned why 'the desert mob has everything set up already, why is the government ignoring Yolŋu?' However, none expressed injustice in the establishment of the Yirrkala renal unit as a result of the status and advocacy of Dr M Yunupiŋu and some were in fact aggrieved that Dr M Yunupiŋu had waited some time for the Yirrkala facility to be funded. Other interlocutors meanwhile articulated a desire to emulate communities in Central Australia that had established their own dialysis services through their own funds, with some also attracting partial government funding. The Yirrkala Renal Unit had been established through the social capital of Dr M Yunupiŋu and the mobilisation of *bala-räli* through co-contributions of Yolŋu disease prevention efforts, customary treatment and biomedicine. Many interlocutors, however, expressed desires to use Yolŋu financial capital to compel further government funding for services throughout the region through material forms of exchange and co-contribution.

[40] Dr G Yunupiŋu was awarded an honorary doctorate by the University of Sydney.

At Purple House's Darwin office one day, when I arrived to observe a Galiwin'ku patient meeting, a patient advocate, a man originally from a remote Northern Territory community that had succeeded in establishing its own renal services, handed Helen a slip of paper. Helen called me over, introducing me to the man, whom she had previously mentioned in admiring terms. The slip held information about the next meeting of the Top End Patient Advisory and Advocacy Committee, a patient representative body, of which Helen was a member. Although the patient advocate described the purpose of the Committee as a forum for patients to raise concerns about their treatment, Helen's interest in participating in the Committee stemmed from a desire to find out how patients from other areas of the Northern Territory had been able to fund dialysis facilities in their communities, including through the use of mining royalties and art sales.

On another occasion, Bu<u>l</u>anydjan described similar hopes of replicating the achievements of other patients who had established their own renal services and of avoiding complete reliance on government funding. She explained that at Lajamanu, a remote community in Central Australia, mining royalties were used to fund nurses' wages:

> *Lajamanu… they don't rely on government all the time…. That's why we are trying, asking Lajamanu help us. How we can get Balanda* (nurses) *to work in our community. And they said we raised up our own money, get from royalty money, chuck into the cup.* (Then) *ask for money from government.*

Several other interlocutors described similar desires to Bu<u>l</u>anydjan of avoiding complete dependency on government funding. While some were aggrieved at the greater recognition apparently bestowed by governments on the care needs of Central Australian and Tiwi patients, desires for greater access to government funding did not necessarily equate to attempts to obtain universal free healthcare.

Some interlocutors had been lobbying Miwatj Health and its board, comprised of Yolŋu leaders, to take responsibility for renal services for the region through similar strategies. Eddie Mulholland, the Miwatj Health CEO, admitted to me in an interview that expansion of remote dialysis services was consistently raised at every board meeting. Yolŋu patients at times expressed frustration that Miwatj Health was not acting quickly enough. Aboriginal Community Controlled Health Organisations such as Miwatj Health contend with the unenviable position of reporting their activities and expenditure to boards as well as government funders. At the time, Miwatj Health were also gradually taking over several health centres in north east Arnhem Land previously operated by the Northern Territory Government, and some patients saw ambivalence in Miwatj's provision of dialysis as raising questions about the legitimacy of its expansion to other communities in the region. As Fred Myers (1986) argued in relation to Pintupi and their perspectives about the legitimacy of the Australian state, the legitimacy

of Miwatj's authority was closely connected to the responsibility it accepted for renal patients' care needs.

In 2014, Miwatj Health held a forum on remote dialysis, inviting representatives from other Aboriginal Community Controlled Health Organisations that had established their own dialysis services to give presentations. Participants described the event as a momentous occasion, in which a sense of possibility and optimism pervaded, and through which bonds of solidarity and mutuality were established with Purple House and other Aboriginal Community Controlled Health Organisations providing renal services. However, the Commonwealth Minister for Indigenous Affairs, who was in attendance, when questioned about his government's contribution, only responded that dialysis services were the responsibility of the Northern Territory Government. The funding stalemate thus continued.

Undeterred, a coalition of Yolŋu organisations and one Anindilyakwa organisation from nearby Groote Eylandt announced a matched funding proposal at the 2017 Garma Festival. The annual Festival is held at a homeland in north east Arnhem Land by the Yothu Yindi Foundation. lt attracts Indigenous leaders from across Australia as well as Prime Ministers and Opposition Leaders, and often serves as a forum for major policy announcements. In 2017, the major theme of the conference was the potential for recognition of Indigenous Australians in the Australian Constitution and political agreement-making, however a key forum was also dedicated to end stage kidney disease (Yothu Yindi Foundation 2017a). A panel of Miwatj staff, health experts and renal patients described the scourge of kidney disease. A Miwatj staff member, a Balanda man, after addressing the audience in Yolŋu matha and English, announced the proposal. Miwatj Health[41], along with the Arnhem Land Progress Aboriginal Corporation, the Gumatj Corporation (which receives mining royalties) and the Anindilyakwa Land Council would together contribute $680,000. The coalition proposed matched funding from the Commonwealth and Northern Territory Governments (Thorpe 2017). The contributions of Yolŋu and Anindilyakwa organisations were described by the Miwatj staff member as indexical of the critical need for renal services in the region. However, both governments rejected the proposal, continuing to attempt to hold one another responsible for renal services in remote areas, while the Prime Minister also refused to respond to Indigenous leaders' demands for Constitutional recognition at the event.

[41] Although Miwatj Health is a not-for-profit organisation, income earned through claims to the Medicare Benefits Schedule and the National Disability Insurance Scheme enable it to earn profits that can be invested in other activities.

Drawing on social and financial debts among Yolŋu to fund dialysis at Galiwin'ku

Some Yolŋu interlocutors who had been lobbying Miwatj Health to extend renal services throughout north east Arnhem Land became tired of waiting for change. Mr Muŋul̲purr expressed his weariness of empty commitments, explaining to me that 'lots of Balanda come'. Impersonating the paternalism of Balanda workers in remote communities, gently patting my knee, he continued, 'it's okay, we'll fix it for you, we'll do it next year'. However, in reality, Mr Muŋul̲purr said, 'Balanda always gets an idea and then leaves'. In the meantime, people are dying, he added, including his late brother. Some interlocutors' frustration with the lack of progress led them to turn away from government funding avenues. Waymamba thought that 'instead of begging the government to give us something we should ask our own people, our own relations'.

Some Yolŋu sought to fund remote dialysis services by recalling social debts existing among Yolŋu. In the Galiwin'ku dialysis pilot, discussed in the previous chapter, Miwatj Health funded nurses' wages while the Arnhem Land Progress Aboriginal Corporation paid for patients' travel. Many thought that ALPA should be contributing more, and looked to the Corporation to fund permanent dialysis services. One woman was dismissive of the $70, 000 ALPA had provided for the Galiwin'ku pilot, retorting, 'that's peanut money'. Through the corporation's business model, community stores and other businesses turned profits, which were reinvested in community development projects (Arnhem Land Progress Aboriginal Corporation 2017). Many interlocutors resented the high price of groceries charged at stores that enjoyed monopoly status in north east Arnhem Land communities, although prices may have at least partially reflected transport costs and lack of economies of scale in remote communities (see Chapter 6). Some also linked the soft drinks and take away foods sold at stores to the emergence of end stage kidney disease amongst Yolŋu. Mr Muŋul̲purr protested, 'they're getting rich from selling people rubbish food… people are slowly dying'. The corporation's profits were seen to be a debt owed to renal patients.

One Yolŋu interlocutor also sought to recall financial debts existing among Yolŋu in his efforts to fund dialysis at Galiwin'ku. In the backblocks of Darwin one morning, Mr Muŋul̲purr, accompanied by his wife Sally and me, attempted to put his funding strategy into action. At the reception of Skinnyfish Music, the record label of Dr G Yunupiŋu, Mr Muŋul̲purr introduced me to Mark, the Skinnyfish director. The tall Caucasian man explained he had known Mr Muŋul̲purr since he was 'this high', placing his hand against his hip. Sally insisted that I refer to Mark as *ŋapipi* (mother's brother), as he had been adopted by her brother as another brother. Mark jested that he and Sally were from 'one mother, one father'.

Mr Muŋuḻpurr and I had come to request the assistance of Skinnyfish in recording some of Mr Muŋuḻpurr's songs for a short documentary we were making with other interlocutors about our research. Mr Muŋuḻpurr had acquired knowledge of ceremonial songs that carried particular *rom* (customary law) and status. He had also been a member of a rock band in younger days, performing vocals and guitar. The songs he had written combined lyrics about his ancestral connections with contemporary and gospel styles of music. Mark responded that the recordings would cost us *rrupiya* (money), but after Mr Muŋuḻpurr reminded him that he, Mr Muŋuḻpurr, had given permission for Dr G Yunupiŋu to record one of his songs on one of the artist's albums without requesting royalties, Mark agreed to 'do it family way', for free. Following the affirmative response, Mr Muŋuḻpurr went on to discuss his plans to hold a music festival at Galiwin'ku to raise funds for additional dialysis machines. As noted in Chapter Seven, the Galiwin'ku renal ready room only contained two dialysis chairs, which were insufficient to provide treatment to all patients from the town and its surrounding homelands. Mr Muŋuḻpurr suggested that Skinnyfish might make sound equipment available for the festival, as well as providing a donation of funds, to which the record label later also agreed. Mr Muŋuḻpurr and other interlocutors had already discussed plans to ask younger relatives who were musicians, performing artists and dancers in a dance troupe, some of them enjoying commercial success and touring Australia, to perform at the benefit gig, also drawing on interdependencies and practices of generalised reciprocity within family groups to hold the festival. Responsibility could be more readily compelled through established relationality and recognised interdependency.

Although Mr Muŋuḻpurr also appealed to other organisations for funds and assistance, the Galiwin'ku music festival had not proceeded at the time of writing. Mr Muŋuḻpurr unexpectedly passed away soon after the Skinnyfish meeting. As his life support was switched off at Royal Darwin Hospital, while perhaps 50 grieving relatives looked on, and his body was transported to the morgue, one of his sisters remembered him as a man who 'looked after his family and the whole community'.

While the concept of *bala-räli* emerges from a Yolŋu cosmology, it has the potential to resonate with health policy objectives by establishing a public ethics of care and by mobilising interdependent relations. The values of *bala-räli*, of co-contribution, equality and respect, overlap with policy agendas of healthcare enacted through shared responsibility. Claims for renal services advanced by Dr M Yunupiŋu and his supporters, through ideas of cultural exchange and partnership in caring for renal patients and in preventing kidney disease, ultimately proved successful. Although the matched funding proposal launched by Yolŋu and Anindilyakwa organisations was ultimately rejected, similar proposals from Indigenous people from other parts of the Northern Territory have been taken up by governments.

In dialysis funding proposals, and through *bala-räli*, Yolŋu attempt to refigure the terms of their care and their relationship with the state and to enact a relational mode of sovereignty. As Cattelino argued (2008), a relational mode of sovereignty exists beyond an abstract legal status, and is located in everyday practice. Yolŋu sovereignty claims are articulated and performed in dialysis co-funding proposals, through their relationships with health professionals who respect Yolŋu law, in bilingual education programs they have developed, and their extension of diplomatic relations to other peoples and governments. Through *bala-räli*, Yolŋu attempt to mobilise interdependent relations between themselves and governments. While Yolŋu proposals for co-contributions to renal services in north east Arnhem Land by Yolŋu organisations and governments can be understood as a response to neoliberal times, I argue, they are premised on Yolŋu values of care, and represent renewed attempts to enact an interdependent, relational mode of sovereignty and make governments responsible to them. The Australian state refuses to recognise legal or relational modes of Indigenous sovereignty, and the Closing the Gap framework and its policy objectives of statistical equality remain manifestly inadequate to the task of addressing past and ongoing dispossession. However, proposals advanced by Yolŋu and other Indigenous people for co-contributions to renal services in their communities, which have enjoyed some limited success, turn neoliberal responsibilisation agendas on their head. Through *bala-räli*, by mobilising interdependencies and positioning themselves as partners of governments, Yolŋu establish moments of recognition and commensuration with government policy agendas.

A public ethics of care: Towards a care-ful sovereignty and health policy

Through *bala-räli,* Yolŋu practice care as a political relation. Feminist theorists have placed care in the domains of politics and citizenship through analysis of women's unremunerated household labour and its implications for social contracts between citizens and states (Sevenhuijsen 1998; Thelen 2015; Tronto 1993). An analysis of *bala-räli*, as a political construct of care operating in colonial and neoliberal conditions, enables us to extend our understandings of political qualities and possibilities of care. *Bala-räli* describes relations of care devoid of feminisation and romanticisation, and not confined to private spaces. *Bala-räli* comprises what I denote as a public ethics of care, expressing how people and collectivities relate to one another, how they should act morally and what they owe one another. A public ethics of care provides a means for recognising peoples, as collectivities, and their needs; and

justifies the distribution of resources for care. The potential exists for a public ethics of care to find expression in the recognition of Indigenous sovereignty and in health policy.

Through *bala-räli*, Indigenous sovereignty within settler states can be understood as a relation of care, as an understanding between Indigenous nations and the state of their relation and of what they owe one another. The recognition of Indigenous sovereignty requires recognition of the fundamental inderdependency between Indigenous nations and settler states, and requires moving away from discourses of Indigenous dependency. Indigenous peoples have given up incalculable multitudes in the course of colonisation and the establishment of states, and continue to contribute to the realisation of state agendas, as this thesis has shown. Recognising Indigenous sovereignty requires recognition of Indigenous political structures and fostering compatibility between Indigenous polities and states, not only through formal legal documents such as treaties and constitutions but also in everyday practice. Realising a care-ful Indigenous sovereignty requires moving beyond conflicting or disparate values of care in health and social policy to find points of commensuration.

Through *bala-räli*, Yolŋu also illustrate how health policy can be negotiated through a public ethics of care and through relations of interdependency. In Chapter Four, I showed how care is enacted through interdependent relationships between health professionals and patients, and is essential to the operation of biomedicine. In this chapter I have illustrated how Yolŋu advance proposals for co-contributions to dialysis in their communities through a public ethics of care, based on relations of interdependency and equality between collectivities, and values and practices of partnership, respect, balanced exchange and co-contribution. The ability of the state to provide biomedicine and care to Indigenous people is limited, through (neo)liberal constructs of care that are corrosive of Indigenous sociality, as the ongoing failure to eliminate statistical disparities in biomedical health, and as the health of renal patients in remote areas attests. As Yolŋu recognise, the successful provision of biomedicine to Indigenous people requires their involvement through relations of care. It also requires a broader understanding of contribution, beyond financial value. A public ethics of care is fundamental to effective health policy, and to a care-ful health policy built on respect and the recognition of people and their health needs.

Conclusions

In the previous chapter I argued that healthcare is invoked by Yolŋu in attempts to realise social value. Here, I have argued that healthcare is also intertwined with the broader value that Yolŋu invest in

cultural alterity and political equality, and with their political ambitions to achieve recognition of Yolŋu law and nationhood by the Australian state. Through Yolŋu conceptualisations of health as a relational state, and of end stage kidney disease as a disease of colonial forms of violence and care, Yolŋu connect the epidemic of end stage kidney disease with their place in the Australian state. For Yolŋu, securing access to dialysis on country and enabling elders with end stage kidney disease to return to their communities is integral to the ongoing enactment of customary law and the care of country and of subsequent generations. The fulfilling of Yolŋu healthcare needs, the practice of customary law and the realisation of Yolŋu nationhood all ultimately require recognition by the state.

In Chapters Four and Seven, I argued that health professionals in Northern Territory renal services conceptualised care as a gift that creates dependency and social debts among patients. Health professionals valorised self care, as a form of treatment thought to foster patient independence. In this chapter I have argued that through the Closing the Gap policy framework, healthcare for Indigenous Australians is also understood as a gift of reparation for historic forms of dispossession; and one that should be provided in ways that promote 'mutual respect, mutual resolve and mutual responsibility'. I have shown in this chapter and throughout this thesis that Yolŋu and the Australian state require one another to realise such disparate political objectives and disparate values of care.

In previous chapters I have argued that interdependencies between Yolŋu practices of care and state policy agendas may be exploited by the state, while Yolŋu nations continue to be denied recognition within state institutions. The failure to realise the value of such interdependencies of care, through dialysis on country, may have negative consequences for both Yolŋu and government health policy agendas. In this chapter I have argued that in some circumstances, Yolŋu instrumentalise the state's dependence on their practices of care in the pursuit of social and political value. Through the concept of *bala-räli,* Yolŋu mobilise interdependencies of care to advance their healthcare needs and sovereignty claims through a public ethics of care. In times of post-universal healthcare, renal services are liable to politicisation; and Yolŋu have been active participants in the distributional politics that has ensued. By taking on specific financial and non-financial responsibilities of care for renal patients and for one another, Yolŋu have attempted to compel greater government responsibility for their needs for healthcare. In doing so, they transform neoliberal conceptualisations of care as a relation of dependency and as a gift that assuages a social debt into Yolŋu interdependent relations of care, of respect through the recognition of others' needs, personhood and nationhood.

Conclusion

Interdependencies of care between Yolŋu and the state

This thesis commenced on the Nightcliff foreshore in suburban Darwin, with an ethnographic vignette of Indigenous renal patients who received highly technical and costly dialysis treatment three times a week while being separated from their kin and country and rendered homeless. I conceptualised the care of Yolŋu renal patients as a social, economic and political relation. Care has been conceptualised throughout this thesis as a relation existing within Yolŋu families and between Yolŋu citizens and the Australian state. I posed the following research questions:

- How is the care for Yolŋu renal patients practiced and valued in Yolŋu domestic moral economies and in health and social policy?

- How do the multiple values and practices of care for Yolŋu renal patients in Yolŋu domestic moral economies and in health and social policy interact?

- What are the implications for relations between Yolŋu and the state?

In the following I respond to each research question, discussing the contribution of this thesis to scholarship, before describing the transferability of my thesis. I then discuss the broader implications of this thesis for how we value people and their care.

How is the care for Yolŋu renal patients practiced and valued in Yolŋu domestic moral economies and in health and social policy?

In this thesis I have offered an original contribution to the scholarship of Australian Indigenous societies, describing a Yolŋu ethics of care in the presence of an epidemic of chronic disease. Although

chronic disease epidemics amongst Indigenous populations internationally have attracted substantial scholarly attention, few scholars have considered how chronic illness invokes or transforms care-giving practices in Indigenous families. Margaret Pollak's study (2017) powerfully demonstrates how diabetes and collective practices of care shape sociality and identity in Chicago's Native American community. Here, I have pushed this analysis further, demonstrating how the care of the state is interwoven with Yolŋu care-giving practices, and how chronic disease and medical displacement can in some circumstances sustain, and in others strain, the social fabric of Yolŋu families.

Through conceptualisations of health as a physical and social state, and as a sensory and affective experience, Yolŋu place particular significance on giving and receiving care. In Yolŋu domestic moral economies, care for kin with end stage kidney disease expresses value in a relational self, respect, elders' knowledge, *märr* and intersubjectivity. In short, care for renal patients expresses value in people, relationships and family solidarity. In a Yolŋu ethics and practice of care, care does not denigrate. The giving and receiving of care, understood as a relationship between generations and heavily implicated in social roles, sustains kinship. Indeed, it is through absences of care that Yolŋu describe themselves as being 'disrespected', or devalued, and not fully recognised by their families as kin in need. Through absences of care some, devastatingly, lose hope for life and the will to live. Care in Yolŋu domestic moral economies can thus be understood as sustaining individual and social bodies.

The social value of domestic care for Yolŋu renal patients is realised though generalised reciprocity and relations of interdependency among kin. While Yolŋu with end stage kidney disease were often heavily reliant on their younger carers to assist them with basic physical tasks, renal patients were often also providers of material and non-material forms of care to their kin. Interdependencies of care could extend to interdependencies of personhood. While renal patients required the respect of younger kin caring for them to enact their social roles as elders, younger Yolŋu could also become particular kinds of kin who accept responsibility in relation to others through care-giving roles. Inequalities, asymmetries and interdependencies of age were thus woven into Yolŋu domestic moral economies.

In the anthropology of Australian Indigenous societies, generalised forms of reciprocity among kin have often been foregrounded, particularly through practices of demand sharing (Altman 2011). In international care scholarship, care is also described as necessarily an asymmetric relation (Ellis 2005; Feder Kittay & Feder 2002). Generalised forms of reciprocity, both material and non-material, were also integral to relations of care in Yolŋu domestic moral economies. Relations between kin were not subject to mutual obligation, or a social transaction requiring direct or equal reciprocation, and one

relative's failure to provide care did not necessarily result in the withdrawal of others' contributions. However, in contrast to the body of literature on demand sharing practices, I have emphasised the encompassment of reciprocities among kin in broader webs of interdependency in Yolŋu domestic moral economies. Interlocking material and non-material reciprocities may encompass contributions of labour, knowledge, food, money and shelter.

Patients and carers displaced to Darwin negotiated relations of care in new ways, including through rotating practices of care, the formalisation of carers' responsibilities, exchanges of caring labour between families and through changing expectations of the gendering of care. The realisation of social value through interdependent relations among kin thus necessitated a negotiation of social relations. Care-giving in Yolŋu domestic moral economies did not simply require the subjection of kin to social norms; and invoked agency amongst care-givers and care-receivers in managing one's feelings and desires, sensibilities of responsibility and access to basic material resources.

While other scholars of non-liberal and non-Western forms of agency locate it in bodily pain (Asad 2000), in subjecting oneself to social norms (Mahmood 2001) and in strategic economic dependency (Ferguson, J 2013), here I have developed the concept of a relational form of agency. I have demonstrated how Yolŋu derive strength from intersubjective feeling and relationships to kin and country, and how social conflict and receiving treatment from unknown health professionals renders some passive and incommunicative. I have shown how the quality of my interlocutor's social relations impact on their ability to act on the world. Eirik Saethre (2013) argues that Warlpiri exercise agency by resisting the assimilationist objectives of biomedicine and conforming to stereotypes of passivity. As Saethre describes of Warlpiri, my Yolŋu interlocutors neither rejected biomedicine, nor fully accepted it on its terms. In contrast to Saethre's interlocutors, however, the Yolŋu renal patients I worked with did not describe the low adherence to treatment and lack of participation in medical consultations among some patients as an act of resistance. Patients' agency in relation to their healthcare was attributed to the quality of their social relationships, including with health professionals. A relational mode of agency opens up a new vantage point on Indigenous practices of care and sharing as involving both the fostering and exercise of agency, in contrast to narratives of sharing as passivity and as the succumbing of Indigenous people to social pressures of kinship.

My contributions to the anthropology of care extend existing approaches to the reciprocities of care within families. Many scholars of care in the social sciences have shown familial relations of care to be relations of reciprocity (Alber & Drotbohm 2015; Baldassar & Merla 2014; Heinemann 2015; Thelen 2015). However, few have brought together the anthropology of care with approaches from economic

anthropology. In this thesis I have extended this work through a close engagement with classic economic anthropology gift theory, and by attending closely to social and material dimensions of care. I have described how care is negotiated in Yolŋu domestic moral economics through generalised and balanced forms of reciprocity and relational modes of agency. This approach has enabled me to move beyond the binary dualisms that have often plagued the anthropology of care, of public/private, social/material, romanticism/exploitation. I have illustrated how Yolŋu relational forms of personhood and agency lead to ways of acting within relations of care that do not construct a binary between self-interest and altruism. As the following sections will further discuss, I have shown how chronic disease, displacement and care-giving can lead to desirable and undesirable forms of (inter)dependency for Yolŋu.

The care of the neoliberal state to Yolŋu renal patients expresses value in self care and self sufficiency, not care for others. The ways in which values of self care and self sufficiency are mobilised in health and social policy constructs the responsibilities of patients to themselves, their families and the state in ways that deny the interdependencies of care in Yolŋu families. The governance of social security, through extensive conditionality including income management, expressed value in satisfying one's own subsistence and that of a nuclear family over sharing with others. The governance of public housing, through restrictions on numbers of residents and visitors, expressed value in sedentarisation and hygiene and sanitation over accommodating kin who lacked a place to stay. Self care dialysis expressed value in performing one's own treatment and for some patients, provided the only means of receiving treatment in their communities. Although self care dialysis regimes were in fact reliant on familial relations of care, they necessitated a reorganisation of kin relations in ways that upset interdependencies within families and neglected the needs of carers. Urban models of dialysis and medical risk protocols in Northern Territory renal services expressed value in patients' biomedical health and in reducing staff liability; and not the broader sets of social relations in patients' communities that sustained them, and that patients themselves helped to sustain. Renal patients and their kin who were deemed incapable of such forms of self care and self sufficiency were subjected to various forms of paternalism. The care of the neoliberal state could thus intertwine the benevolent and the coercive.

Through conceptualisations of legitimate and illegitimate dependency, the care of the state is concerned with Yolŋu whose suffering and marginalisation is attributable to poor health, while remaining silent on the needs of their kin experiencing other forms of deprivation and marginalisation. Those defined as legitimately dependent on the state, often including renal patients, were conceptualised as being unable to fulfil economic responsibilities associated with self care and self

sufficiency. Health and social policy frameworks evidently did not expect people classified in this way to also care for others.

The ethics and practice of care that I have described in Yolŋu domestic moral economies contrasts sharply with conceptualisations of care in health and social policy as a burden, as a disruption to productive roles and as a gift that creates dependency. Responsibilities of care could at times be taxing for Yolŋu care-givers. Relations of care in Yolŋu domestic moral economies, however, represented much more than a burden. While bodily, social and economic dependency are deeply stigmatised in liberal thought, for Yolŋu, dependency was only rendered problematic in the absence of kin relationality. Asymmetric social and economic relations among kin, encapsulated within broader relations of material and non-material interdependency, were integral to Yolŋu domestic moral economies.

How do the multiple values and practices of care for Yolŋu renal patients in Yolŋu domestic moral economies and in health and social policy interact?

The care of the state, through health and social policy, is substantially implicated in the domestic moral economies of Yolŋu with end stage kidney disease. Renal patients relied on thrice-weekly dialysis treatment to sustain life, and families marginalised from both customary economies and the formal economy relied heavily on welfare resources. The resources of the state are of course also implicated in the domestic moral economies of middle-class Australian families whose members are employed in the formal economy, including through childcare subsidies, first homeowners' grants, respite care, aged care assistance and income tax relief. However, in contrast, the care of the state participates in the domestic moral economies of Yolŋu renal patients in ways that cast care as a burden of dependency within families and on the state; and in ways that conflict with Yolŋu values and practices of care.

The care of the state, conceptualised in health and social policy as a gift that sustains dependency, is administered through mutual obligation that attempts to instil or compel particular norms of self care and self sufficiency. As David Graeber (2001: 219-220) notes, both gifting and market forms of exchange are premised on the notion of the moral value of reciprocation, or the belief that nobody should get something for nothing. Although contention between Yolŋu values of care and the care of

the state was not always immediately apparent, such as in relationships between patients and their health professionals, conflicting values of care could nevertheless lead to perceptions of mutual exploitation in therapeutic relationships. Through the contending values of care, and concepts in health and social policy of legitimate and illegitimate dependency, questions of the distribution of resources of care are transformed into a politics of behaviour.

In the anthropology of care, state-sponsored healthcare has been described as a gift and a relation of reciprocity between patients and health professionals or states (Andaya 2009; Kyeong Seo 2016). Scholars of healthcare have examined a variety of healthcare regimes, and have tended to foreground social and financial indebtedness among patients and citizens. Through an approach to care that engages with classic gift theory, and through a comprehensive understanding of the contributions patients make to the performance of biomedicine, I have illustrated interdependencies between patients and health professionals. In contrast to the constructs of care embodied by renal service health professionals and in health policy, I have shown how healthcare in renal services can be characterised as a relation of generalised reciprocity. Generalised reciprocities, through which patients participate in their treatment, are fundamental to the successful performance of dialysis.

Values of care in Yolŋu domestic moral economies and in health and social policy were not always diametrically opposed. Among Yolŋu, through relational forms of agency, caring for oneself and achieving longevity were not necessarily always counterposed to caring for others. As John Baldock argues (1997), care is best understood as a social relation, not a good or service to be allocated in various ways. Yolŋu with end stage kidney disease did at times describe their own lives as cut short, mourning their likely lack of longevity. For Yolŋu, however, self care and longevity could represent means to other ends. For Wapiriny, desires for a long and full life were motivated not by personal objectives, but desires to care for grandchildren. He explained to me,

> *I'm still struggling, still walking along slowly, just to keep me alive. … I try best to live longer for my grandson, my granddaughters and other grandsons. So that when they grow up, they're still gonna see me, before I pass, leave them. Because family's important in your life to all of us.*

Wapiriny had successfully protected his grandchildren from the interventions of child protection services, which he accused of failing to respect Yolŋu practices of child care. Devastatingly, Wapiriny did not survive much longer after this statement was made. Like many interlocutors, his untimely death left families without an elder and left life projects incomplete. In contrast to the Closing the Gap policy framework and policy objectives of statistical health equality among Indigenous and non-

Indigenous populations, longevity appeared to be valued by interlocutors such as Wapiriny only insofar as it impacted on social value and relations of care among kin.

Disparate or contending values of care in Yolŋu families and in health and social policy could impact Yolŋu in a variety of ways. In some circumstances, end stage kidney disease and the concept of legitimate dependency in social policy could work to reinforce the performance of social roles and intensify relations of interdependency in Yolŋu families. Relations of care, understood by Yolŋu as an element of the good life, become even more pertinent in an epidemic of chronic disease, through urban displacement and in conditions of economic marginalisation. End stage kidney disease and economic marginalisation could reinforce interdependencies between generations, as vulnerable kin turned to one another for help to get by. Exclusion from the formal economy and displacement from customary economies could further reinforce care-giving as a socially valuable role amongst younger people. The capacity of older renal patients to mobilise welfare resources as well as wages, royalties and sitting fees, and a lack of remuneration of carers, was also liable to reinforce responsibilities to share resources with younger kin.

For some Yolŋu with end stage kidney disease, however, contending values of care among Yolŋu families and in health and social policy could make interdependent relations of care difficult to sustain. This was particularly likely to be the case for younger patients involved in my research, who were more likely to be sleeping rough, to take up drinking, to miss or cease treatment and to suffer domestic violence among my interlocutors. While inadequate care for some younger Yolŋu renal patients could partially reflect their inability to perform social roles associated with age in their families, it was primarily an outcome of their lives being governed in ways that created tensions in the social fabric of Yolŋu families. For younger patients, who were more likely to be categorised as illegitimately dependent on the state, less access to welfare resources could be compounded by urban displacement, which limited their capacity to seek assistance from kin. For Yolŋu, urban displacement entailed increased living expenses and a different structuring of living costs, requiring lump sum payments, which could compromise practices of sharing money and food with kin. The governance of housing could compromise the capacity of Yolŋu to extend shelter to relatives. Patients who were unable to access welfare resources and also unable to seek assistance from kin were likely to find themselves subject to acute bodily and economic precarity. For Yolŋu patients, for whom receiving assistance from kin expressed respect, produced social value and was integral to a relational personhood, being without care or assistance could also entail a loss of one's personal substance, and could make one's life no longer worth living. The threat of insufficient care in Darwin was a far greater concern amongst my interlocutors than the risk of heart attack and insufficient emergency healthcare

in their home communities. In Yolŋu domestic moral economies, the way that the care of the state was conceptualised and provided could threaten the interdependent relations that sustained one and sustained who one was.

What are the implications for relations between Yolŋu and the state?

The care of the state for Yolŋu renal patients and their families is governed through values of self care and self sufficiency and the objective of eliminating dependency; yet governments also rely on Yolŋu care practices to achieve health and social policy agendas. In renal services, self care policy objectives relied on carers to assist renal patients to make dietary and lifestyle changes, remember to take medications, attend large numbers of medical appointments, live with increasing frailty and in some cases, perform their own dialysis treatment. Housing policy frameworks that aimed to reduce the number of people sleeping rough, in a context of long public housing wait lists and disinvestment in public housing, relied on Yolŋu renal patients who had acquired public housing to provide shelter to visiting carers and other kin. Social security policy that provided insufficient subsistence to Yolŋu who were receiving unemployment benefits relied on those receiving higher rates of payment, such as renal patients, and Yolŋu practices of sharing, to ensure that basic subsistence needs were met. Interdependencies between Yolŋu and the state are historic and structural, emerging from overlapping sovereignty claims and the structures of Australian federalism. As scholars of development note, state agendas tend to be parasitic on a multitude of local relations and practices (Ferguson, J 2013; Scott 1998). Relations of interdependency are integral to Yolŋu domestic moral economies, and also to relations between Yolŋu families and the state.

Paradoxically, interdependencies between Yolŋu and the state become particularly salient in neoliberal times. As Andrea Muehlebach argues (2007, 2012), neoliberal states coexist with and require other moral orders present in domestic moral economies. In neoliberal policy, welfare has become more conditional and less universal, the responsibilities of the state to Indigenous people have become more construed in terms of biomedical illness and disputes have increasingly arisen over the obligations of the state to support Indigenous people living in remote areas deemed unproductive in the formal economy. In these circumstances, the state increasingly relies on Yolŋu domestic moral economies to satisfy the basic needs of life of Yolŋu citizens and to achieve policy agendas. My

analysis extends Muehlebach's work on neoliberal governmentality, illustrating how it institutionalises not only precarity but also interdependency between welfare recipients and states.

The conflictual yet interdependent relationship between Yolŋu and the state remains obscured in health and social policy, leading to negative consequences for the state as well as Yolŋu. Moral panics about the dependency of Indigenous Australians on state transfers fail to appreciate the broader material and non-material interdependencies in which dependency is encapsulated. Policy frameworks that marginalise the care practices and sets of social relations on which they depend produce undesirable public policy outcomes. Conflicting meanings and expectations of care in health and social policy could threaten Yolŋu with homelessness and food insecurity. Urban renal services that offer life sustaining treatment through urban displacement constitute interdependencies of care in ways that could lead to poor patient health, both in biomedical terms and in the terms of Yolŋu conceptualisations of health. The low life expectancy of dialysis patients in the Northern Territory, low adherence to treatment amongst some patients and decisions amongst some to cease treatment may be attributable to the social circumstances of patients' lives, in which the care of the state strains the social fabric of kinship and Yolŋu relations with country.

While interdependencies between Yolŋu and the state in the presence of unequal power relations hold the potential of the exploitation of Yolŋu families, Yolŋu have attempted to enact a relational mode of sovereignty, based on recognition of the interdependency that exists between clan-nations and the state. Through processes of reciprocity and co-contribution, including in dialysis co-funding proposals in north east Arnhem Land, Yolŋu have attempted to compel governments to recognise both their sovereignty within the state and their care needs. In articulating a relational mode of sovereignty, Yolŋu practice care as a political relation, and have advanced what I denote as a public ethics of care, expressing how people and collectivities relate to one another, how they should act morally and what they owe one another. The concept of a public ethics of care builds on the work of feminist theorists who place domestic relations of care in the domain of citizenship and social contracts (Sevenhuijsen 1998; Thelen 2015; Tronto 1993), and offers a conceptualisation of care that is not feminised, romanticised or confined to private domains. A public ethics of care provides a new means of conceptualising the everyday practice of citizenship and sovereignty.

The interdependencies of care between Yolŋu and the state that I have described suggest that revisions are required to our ways of conceptualising the relationship between Indigenous peoples and settler states. The encapsulation of Indigenous people within the Australian state is often thought about through the terms of past dispossession and present dependency on the state. Indeed, this is the social contract that has underscored a degree of recognition of Indigenous cultural alterity within

the state and, in an earlier era of Indigenous policy, state support for people residing in homelands including through more flexible social security arrangements. It is this social contract that the neoliberal state is dismantling, through an operating logic of eliminating welfare dependency, compelling participation in the formal economy, withdrawing support for homelands and curtailing care for people defined as illegitimately dependent. The political and economic relations of interdependency that I have described, however, suggest that conceptualisations of health and social policy as providing benefits that create social debts and that legitimate the state determining the terms of the repayment, via compliance with particular Western norms of responsible citizenship, are redundant. Meanwhile, I have also shown that processes of dispossession may continue through contemporary forms of healthcare and these very logics of social debt, that exile people from country, the enactment of law and responsibilities to younger generations of kin. Indigenous sovereignty within settler states can be understood as a relation between Indigenous nations and states of interdependency, as Jessica Cattelino (2008) has argued. I have also shown that the relation between Indigenous nations and settler states is a relation of care, which can be claimed by Indigenous nations and recognised by states through a public ethics of care.

Indigenous sovereignty understood as a relation of interdependency also has implications for how we conceptualise entitlements to care through health and social policy, and the obligations of the state to Indigenous people and collectivities, both in quantity and nature. It suggests that we need to conceptualise the care of the state as Yolŋu understand the care in families, not as entitlements that are earned, but as a relation productive of particular kinds of society and polity. Relations of care are implicated in the sovereignty aspirations of Indigenous collectivities as well as the sovereignty claims of the Australian state.

My conceptualisation of the relation between Yolŋu and the Australian state as a relation of interdependency, while perhaps not entirely shared by my interlocutors, has some resonance with their perspectives and desires to realise *bala-räli*. Yolŋu themselves emphasise social relations and social action in the constitution of states of health and illness. Although some interlocutors expressed concern about their dependency on the state, as dependency in the absence of relationality, one interlocutor noted the contribution made by Yolŋu to state agendas. I had intended to produce a series of short films in collaboration with some interlocutors to share the experiences of renal patients with other Balanda and Yolŋu. However, some expressed a desire to instead produce films that communicated means of preventing kidney disease to their younger relatives. In the end, we satisfied both objectives. One of those involved complained during editing of the lack of renal services in her

community, commenting that 'the government is angry at Yolŋu, they don't see the good things that Yolŋu do'.

Transferability

Yolŋu interlocutors' experiences of end stage kidney disease and displacement in some respects are likely to be particular. As a swathe of ethnographic work documents, Yolŋu social organisation and beliefs and practices associated with health and the human body may differ to the beliefs, practices and structures of other Australian Indigenous societies (eg: Berndt 1976; Burbank et al. 2008; Fisher 2016; Keen 2004; Myers 1986). As Yolŋu represent one of the largest Indigenous collectivities in the Northern Territory in numeric terms, and are thought to represent one of the largest groups present in Darwin (Christie & Greatorex 2004), Yolŋu renal patients and their kin may have had larger social networks in Darwin than Indigenous renal patients from other parts of the Northern Territory. Unlike many Indigenous people, Yolŋu were not generally alienated from their land during earlier periods of colonisation and urban displacement due to end stage kidney disease may thus be experienced as a primary form of dispossession.

Nevertheless, my thesis, on the interdependent nature of Yolŋu citizenship of the Australian state, may be broadly transferrable to other Australian Indigenous societies. Most of the Yolŋu care practices that I have described have been extensively documented across Australian Indigenous societies, as I have indicated throughout this thesis. The ways in which Yolŋu patients are cared for by the state are also not unique. The Closing the Gap policy framework and social security policy are national in their application. Increasing housing insecurity and declining investment in public housing are a national and international phenomenon. Other Australian States and Territories have generally adopted similar hub and spoke models of dialysis services. This was a point reinforced to me in a chance encounter in a Canberra café with an Indigenous man who had been required to emigrate from the New South Wales south coast and depart from his familial networks in the region in order to receive dialysis treatment in the Australian capital. Hub and spoke models are increasingly being adopted to deliver other health and social services to remote Indigenous communities (Markham & Doran 2015). Disability studies and social gerontology scholars have shown that the conceptualisations of care in Australian health and social security policy that I have described as casting care as a burden for care-givers and care-receivers alike are deeply embedded in liberal thought (eg: Fine, MD 2007a; Weicht 2011). Interdependent relations of care, wrought through contending values and practices, are

likely to characterise the relations between the Australian state and Indigenous renal patients, as well as Indigenous people with other serious medical conditions.

Valuing care and valuing people differently

The devaluing of care to the most vulnerable members of our societies in Australian public policy is evident in a multitude of recent royal commissions and reviews. Since just 2016, three Royal Commissions into Aged Care Quality and Safety; Disability; and the Detention and Protection of Children in the Northern Territory have all been initiated, in addition to a Review of Forensic Mental Health and Disability Services in the Northern Territory. They have revealed the paternalism, neglect, abuse and exploitation that may take place when care must be earned, care is narrowly defined as treatment and people who require care are dehumanised as dependents on institutions, to be allocated minimal funding.

Many more Australians, both Indigenous and settler, will require care in the future. Both Indigenous and non-Indigenous Australians are living longer and are subject to accelerating rates of chronic disease (Australian Government 2020). Global economic transformations are also likely to exclude many of the world's people, indigenous and settler, from future formal economies (Murray Li 2014: 2-4). Our changing circumstances require new ways of thinking about the kind of living that we are owed, and that we owe each other, beyond a social contract based on historic dispossession and present dependency, beyond (male) productive labour in the formal economy and beyond neoliberal self care and self sufficiency. We need new ways of attending to the universalism and particularism of care and of realising interdependencies between families and the state in mutually productive ways. In health and social policy, we require means of valuing people and collectivities for who they are or might become, and not for who we might want them to be.

Bibliography

Aboriginal Hostels Limited 2019, *New Approaches to Meeting Renal Accommodation Demand: Project Brief*, Canberra, AHL.

Ahern, L 2001, 'Language and Agency', *Annual Review of Anthropology*, vol. 30, pp. 109-137.

Alber, E & Drotbohm, H (eds) 2015, *Anthropological Perspectives on Care*, New York, Palgrave Macmillan.

Alexander, C, Bruun, M & Koch, I 2018, 'Political economy comes home: on the moral economies of housing', *Critique of Anthropology*, vol. 38, no. 2, pp. 121-139.

Altman, J 1987, *Hunter Gatherers Today: An Aboriginal economy in north Australia*, Canberra, Australian Institute of Aboriginal Studies.

Altman, J 2001, *Sustainable development options on Aboriginal land: The hybrid economy in the twenty-first century*, CAEPR Discussion Paper No. 226, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Altman, J 2007, 'Alleviating poverty in remote Indigenous Australia: The role of the hybrid economy', *Development Bulletin*, vol. 72, pp. 47-51.

Altman, J 2009a, *Beyond Closing the Gap: Valuing Diversity in Indigenous Australia*, CAEPR Working Paper No. 54, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Altman, J 2009b, *Beyond Closing the Gap: Valuing Diversity in Indigenous Australia*, CAEPR Working Paper, Canberra, AN University.

Altman, J 2011, 'A Genealogy of 'Demand Sharing': From pure anthropology to public policy', in Y Musharbash & M Barber (eds), *Ethnography & the Production of Anthropological Knowledge: Essays in honour of Nicolas Peterson*, Canberra, ANU Press, pp. 187-200.

Altman, J 2018a, ''The Main Thing Is to Have Enough Food': Kuninjku Precarity and Neoliberal Reason', in C Gregory & J Altman (eds), *The Quest for the Good Life in Precarious Times: Ethnographic Perspectives on the Domestic Moral Economy*, Canberra, ANU Press, pp. 163-196.

Altman, J 2018b, 'Raphael Lemkin in Remote Australia: The Logic of Cultural Genocide and Homelands', *Oceania*, vol. 88, no. 3, pp. 336-359.

Altman, J & Hinkson, M (eds) 2007, *Coercive Reconciliation: Stabilise, Normalise, Exit Aboriginal Australia*, North Carlton, Arena Publications.

Altman, J & Sanders, W 1995, 'From exclusion to dependence: Aborigines and the welfare state in Australia', in J Dixon & RP Scheurell (eds), *Social welfare with indigenous peoples*, London and New York, Routledge, pp. 206-229.

Amrith, M 2017, *Caring for Strangers: Filipino Medical Workers in Asia*, Copenhagen, NIAS Press.

Andaya, E 2009, 'The Gift of Health: Socialist Medical Practice and Shifting Material and Moral Economies in Post-Soviet Cuba', *Medical Anthropology Quarterly*, vol. 23, no. 4, pp. 357-374.

Anderson, I 1995, 'Bodies, disease and the problem of Foucault', *Social Analysis: The International Journal of Social and Cultural Practice*, vol. 37, pp. 67-81.

Anderson, K, Cunningham, J, Devitt, J, Preece, C & Cass, A 2012, '"Looking back to my family": Indigenous Australian patients' experience of haemodialysis', *BMC Nephrology*, vol. 13, no. 114.

Anderson, K, Devitt, J, Cunningham, J, Preece, C, Jardine, M & Cass, A 2012, 'If you can't comply with dialysis, how do you expect me to trust you with transplantation? Australian nephrologists' views on indigenous Australians''non-compliance' and their suitability for kidney transplantation', *International Journal for Equity in Health*, vol. 11, no. 21.

Anglicare Australia 2018, *2018 Rental Affordability Snapshot: Regional Reports and Snapshots*, Canberra, Anglicare Australia.

Appadurai, A (ed.) 1986, *The Social Life of Things: Commodities in cultural perspective*, Cambridge, Cambridge University Press.

Arnhem Land Progress Aboriginal Corporation 2017, *Annual Report 2016-17*, Darwin, ALPA Corporation.

Arnold, D 1993, *Colonizing the Body: State Medicine and Epidemic Disease in Nineteenth-Century India*, Berkeley, University of California Press.

Arnold, P 2001, 'Rethinking Moral Economy', *The American Political Science Review*, vol. 95, no. 1, pp. 85-95.

Asad, T 2000, 'Agency and pain: An exploration', *Culture and Religion*, vol. 1, no. 1, pp. 29-60.

Asad, T 2004, 'Where are the Margins of the State?', in V Das & D Poole (eds), *Anthropology in the Margins of the State*, Santa Fe, School of American Research Press, pp. 279-288.

Aulino, F 2012, *Senses and Sensibilities: The Practice of Care in Everyday Life in Northern Thailand*, PhD thesis, Harvard University.

Austin-Broos, D 2003, 'Places, Practices, and Things: The Articulation of Arrernte Kinship with Welfare and Work', *American Ethnologist*, vol. 30, no. 1, pp. 118-135.

Austin-Broos, D 2009, *Arrernte Present, Arrernte Past: Invasion, Violence, and Imagination in Indigenous Central Australia*, Chicago and London, University of Chicago Press.

Australia and New Zealand Dialysis and Transplant Registry 2016, *38th Annual Report*, Adelaide, ANZDATA Registry.

Australia and New Zealand Dialysis and Transplant Registry 2018, *41st Annual Report*, Adelaide, ANZDATA Registry.

Australian Bureau of Statistics 2006, *Map of Australia – Discrete Indigenous communities and the Australian standard geographical classification remoteness structure* Cat. no. 4706.0.30.001, Canberra, ABS.

Australian Bureau of Statistics 2016a, *Census of Population and Housing Aboriginal and Torres Strait Islander Peoples Profile, Northern Territory*, Cat. no. 2002.0, ABS, Canberra.

Australian Bureau of Statistics 2016b, *Census of Population and Housing General Community Profile, Northern Territory*, Cat. no. 2001.0, ABS, Canberra.

Australian Bureau of Statistics 2016c, *East Arnhem General Community Profile*, Cat. no. 2001.0, ABS, Canberra.

Australian Bureau of Statistics 2016d, *Greater Darwin General Community Profile*, Cat. no. 2001.0, ABS, Canberra.

Australian Bureau of Statistics 2018, *Census of Population and Housing: Estimating homelessness, 2016*, Cat. no. 2049.0, Canberra.

Australian Council of Social Service 2019, *Raise the Rate*, Accessed 27 Aug 2019 https://raisetherate.org.au.

Australian Government 2020, *Closing the Gap Report 2020*, Canberra, National Indigenous Australians Agency.

Australian Government Department of Health 2019, *Medicare Benefits Schedule - Item 13105*, Accessed 14 May 2019 http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=13105&qt=ItemID.

Australian Government Department of Social Services 2019, *Multi-agency Government Submission to the Senate Community Affairs References Committee inquiry on the Adequacy of Newstart and related payments and alternative mechanisms to determine the level of income support payments in Australia*, Canberra, Po Australia.

Australian Health Ministers' Advisory Council 2015, *Aboriginal and Torres Strait Islander Health Performance Framework 2014 Report*, Canberra, AHMAC.

Australian Institute of Health and Welfare 2015a, *Cardiovascular disease, diabetes and chronic kidney disease - Australian facts: Aboriginal and Torres Strait Islander people*, Cardiovascular, diabetes and chronic kidney disease series, Cat. no. CDK 5, Canberra, AIHW.

Australian Institute of Health and Welfare 2015b, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*, Canberra, AIHW.

Australian Institute of Health and Welfare 2019, *Chronic Kidney Disease*, Cat. no. CDK 16, AIHW, Canberra.

Baer, H, Singer, M & Susser, I 2013, *Medical Anthropology and the World System: Critical Perspectives*, 3rd edn., Santa Barbara, Praeger.

Bailie, R & Wayte, KJ 2006, 'Housing and health in Indigenous communities: key issues for housing and health improvement in remote Aboriginal and Torres Strait Islander communities', *Australian Journal of Rural Health*, vol. 14, no. 5, pp. 178-183.

Baldassar, L & Merla, L 2014, 'Introduction: Transnational Family Caregiving Through the Lens of Circulation', in L Baldassar & L Merla (eds), *Transnational Families, Migration and the Circulation of Care: Understanding Mobility and Absence in Family Life*, New York and Oxon, Routledge, pp. 3-24.

Baldock, J 1997, 'Social Care in Old Age: More Than a Funding Problem', *Social Policy and Administration*, vol. 31, no. 1, pp. 73–89.

Barber, M 2008, 'A Place to Rest: Dying, Residence and Community Stability in Remote Arnhem Land', in K Glaskin, M Tonkinson, Y Musharbash & V Burbank (eds), *Mortality, Mourning and Mortuary Practices in Indigenous Australia*, Surrey and Burlington, Ashgate, pp. 153-169.

Barnes, M, Brannelly, T, Ward, L & Ward, N 2015, 'Introduction: the critical significance of care', in M Barnes, T Brannelly, L Ward & N Ward (eds), *Ethics of care: Critical advances in international perspective*, Bristol, Policy Press.

Bartlett, B & Boffa, J 2005, 'The impact of Aboriginal community controlled health service advocacy on Aboriginal health policy', *Australian Journal of Primary Health*, vol. 11, no. 2, pp. 53-61.

Beck, U 1992, *Risk Society: towards a new modernity*, London, Thousand Oaks.

Beckett, J 1987, *Torres Strait Islanders: custom and colonialism*, Cambridge, Cambridge University Press.

Bell, HS, Odumosu, F, Martinez-Hume, AC, Howard, HA & Hunt, LM 2019, 'Racialized Risk in Clinical Care: Clinician Vigilance and Patient Responsibility', *Medical Anthropology*, vol. 38, no. 3, pp. 224-238.

Beneria, L 1979, 'Reproduction, production and the sexual division of labour', *Cambridge Journal of Economics*, vol. 3, pp. 203-225.

Bennett, E, Manderson, L, Kelly, B & Hardie, I 1995, 'Cultural factors in dialysis and renal transplantation among Aborigines and Torres Strait Islanders in North Queensland', *Australian Journal of Public Health*, vol. 19, no. 6, pp. 610-615.

Berndt, R 1962, *An Adjustment Movement in Arnhem Land, Northern Territory of Australia*, Paris, Mouton and Co.

Berndt, R 1976, 'Territorality and the problem of demarcating sociocultural space', in N Peterson (ed.), *Tribes and Boundaries in Australia*, Canberra, Australian Institute of Aboriginal Studies, pp. 133-161.

Bessarab, D & Ng'andu, B 2010, 'Yarning About Yarning as a Legitimate Method in Indigenous Research', *International Journal of Critical Indigenous Studies*, vol. 3, no. 1, pp. 37-50.

Biddle, N 2010, 'Indigenous migration and the labour market: A cautionary tale', *Australian Journal of Labour Economics*, vol. 13, no. 3, pp. 313-330.

Biehl, J 2007, *Will to Live: AIDS therapies and the politics of survival*, Princeton and Oxford, Princeton University Press.

Biehl, J 2013, *Vita: Life in a Zone of Social Abandonment*, Berkeley, University of California Press.

Birdsall-Jones, C & Christensen, W 2007, *Aboriginal housing careers in Western Australian towns and cities*, AHURI Positioning Paper No. 95, Australian Housing and Urban Research Institute, Perth.

Borneman, J 1997, ' Caring and being cared for: displacing marriage, kinship, gender and sexuality', *International Social Science Journal*, vol. 49, no. 4, pp. 573-584.

Bornstein, E 2007, 'Harmonic dissonance: reflections on dwelling in the field', *Ethos*, vol. 72, no. 4, pp. 483-508.

Bourdieu, P 1977, *Outline of a Theory of Practice*, Cambridge, Cambridge University Press.

Bray, R, Gray, M, Hand, K & Katz, I 2015, 'Compulsory Income Management in the Northern Territory – evaluating its impact', *Australian Journal of Social Issues*, vol. 50, no. 4, pp. 373-396.

Breen, J 2017, 'Galiwin'ku locals pay tribute to 'kind, understanding' pilots killed in crash', *ABC News* 26 October, Accessed 3 July 2020 https://www.abc.net.au/news/2017-10-26/galinwinku-locals-tribute-pilots-in-darwin-plane-crash/9087166.

Brooks, S 2015, *Indigenous health organisations unite to improve remote dialysis treatment*, https://www.abc.net.au/news/2015-02-16/dialysis-agreement-between-two-indigenous-health-organisations/6107154.

Broome, R 2001, *Aboriginal Australians: Black Responses to White Dominance 1788-2001*, 3rd edn., Crows Nest, Allen and Unwin.

Brotherton, PS 2012, *Revolutionary Medicine: Health and the body in post-Soviet Cuba*, Durham and London, Duke University Press.

Buch, E 2013, 'Senses of care: Embodying inequality and sustaining personhood in the home care of older adults in Chicago', *American Ethnologist*, vol. 40, no. 4, pp. 637–650.

Buch, E 2015, 'Anthropology of Ageing and Care', *Annual Review of Anthropology*, vol. 44, pp. 277-293.

Burbank, V 1988, *Aboriginal Adolescence: Maidenhood in an Australian community*, New Brunswick and London, Rutgers University Press.

Burbank, V 2006, 'From Bedtime to On Time: Why Many Aboriginal People Don't Especially Like Participating in Western Institutions', *Anthropological Forum*, vol. 16, no. 1, pp. 3-20.

Burbank, V 2011, *An Ethnography of Stress: The Social Determinants of Health in Aboriginal Australia*, New York, Palgrave Macmillan.

Burbank, V 2017, 'The embodiment of sorcery: Supernatural aggression, belief and envy in a remote Aboriginal community', *The Australian Journal of Anthropology*, vol. 28, no. 3, pp. 286-300.

Burbank, V, Glaskin, K, Musharbash, Y & Tonkinson, M 2008, 'Introduction: Indigenous Ways of Death in Australia', in K Glaskin, M Tonkinson, Y Musharbash & V Burbank (eds), *Mortality, Mourning and Mortuary Practices in Indigenous Australia*, Surrey and Burlington, Ashgate, pp. 1-20.

Bureau of Meteorology 2020, *Climate statistics for Australian locations: Darwin Airport*, Product IDCJCM0029, BOM, Melbourne.

Burgess, C, Johnston, F, Berry, H, McDonnell, J, Yibarbuk, D, Gunabarra, C, Mileran, A & Bailie, R 2009, 'Healthy country, healthy people: the relationship between Indigenous health status and 'caring for country'', *Medical Journal of Australia*, vol. 190, no. 10, pp. 567-572.

Burnette, L & Kickett, M 2009a, 'Dislocation and Dialysis in Aboriginal Patients with Renal Failure', *Aboriginal and Islander Health Worker Journal*, vol. 33, no. 4, pp. 10-13.

Burnette, L & Kickett, M 2009b, ''You are just a puppet': Australian Aboriginal people's experience of disempowerment when undergoing treatment for end-stage renal disease', *Renal Society of Australasia Journal*, vol. 5, no. 3, pp. 113-118.

Byrne, C 2018, *Interview with Age Discrimination Commissioner*, Mornings, ABC local radio Darwin, 28 Aug.

Cameron, JI, Whiteside, C, Katz, J & Devins, GM 2000, 'Differences in quality of life across renal replacement therapies: A meta-analytic comparison', *American Journal of Kidney Disease*, vol. 35, no. 4, pp. 629–637.

Campbell, D 2011, 'Application of an integrated multidisciplinary economic welfare approach to improved wellbeing through Aboriginal caring for country', *The Rangeland Journal*, vol. 33, no. 4, pp. 365-372.

Carson, B, Dunbar, T, Chenhall, R & Bailie, R (eds) 2007, *Social Determinants of Indigenous Health*, Crows Nest, Allen and Unwin.

Cass, A, Brown, A, S, T, Snelling, P, Devitt, J, Thomas, M, Howard, K & McGilvray, A 2011, *Central Australian Renal Study: Part 3 Technical Report*, The George Institute for Global Health, prepared for the Australian Department of Health and Ageing, Sydney.

Cass, A, Cunningham, J, Snelling, P, Wang, Z & Hoy, W 2004, 'Exploring the pathways leading from disadvantage to end-stage renal disease for Indigenous Australians', *Social science and medicine*, vol. 58, pp. 767-785.

Cass, A, Cunningham, J, Wang, Z & Hoy, W 2001, 'Regional variation in the incidence of end-stage renal disease in Indigenous Australians', *Medical Journal of Australia*, vol. 175, no. 1, pp. 24-27.

Cass, A, Feyer, A, Brown, A, Snelling, P & Howard, K 2011, *Central Australian Renal Study - Final Report*, The George Institute for Global Health, prepared for the Australian Department of Health and Ageing, Sydney.

Cass, B 2004, 'Contested Debates about Citizenship Rights to Welfare: Indigenous People and Welfare in Australia', in D Austin-Broos & G Macdonald (eds), *Culture, Economy and Governance in Aboriginal Australia: Proceedings of a Workshop of the Academy of Social Sciences in Australia*, Sydney, University of Sydney Press, pp. 95-108.

Castro, A & Singer, M 2004, 'Introduction to Anthropology and Health Policy: A Critical Perspective', in A Castro & M Singer (eds), *Unhealthy Health Policy: A Critical Anthropological Examination*, Maryland, AltaMira Press, pp. xi-xx.

Cattelino, J 2008, *High Stakes: Florida Seminole Gaming and Sovereignty*, Durham and London, Duke University Press.

Cawte, J 1996, *Healers of Arnhem Land*, Sydney, UNSW Press.

Centrelink 2019, *Centrelink individuals*, Accessed 12 March 2019 https://www.humanservices.gov.au/.

Charles Darwin University 2014, *Yolŋu Matha Dictionary*, Accessed 10 April 2018 http://yolngudictionary.cdu.edu.au/.

Chattoo, S & Ahmad, WIU 2008, 'The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice', *Sociology of Health and Illness*, vol. 30, no. 4, pp. 550-564.

Chenhall, R & Senior, K 2017, 'Living the Social Determinants of Health: Assemblages in a Remote Aboriginal Community', *Medical Anthropology Quarterly*, vol. 32, no. 2, pp. 177–195.

Cheshire, B 2009, *Message From Mr Yunupingu*, Australian Story, Brisbane, 19 October.

Christie, M, Dhamarrandji, M, Gapany, D, Gaykamaŋu, W, Gurruwiwi, D, Guyula, Y, Binalany, T, Guthadjaka, K, Pascoe, G & Greatorex, J 2013, *More Than a Roof Overhead: Consultation for Better Housing Outcomes (Year 1)*, Darwin, Charles Darwin University.

Christie, M & Gaykamaŋu, W 2004, *Yolŋu languages and culture: Gupapuyŋu study notes*, Darwin, Charles Darwin University.

Christie, M & Greatorex, J 2004, 'Yolngu Life in the Northern Territory of Australia: The Significance of Community and Social Capital', *Asia Pacific Journal of Public Administration*, vol. 26, no. 1, pp. 55-69.

Christie, M, Verran, H, Cathcart, J, van Weeren, T, Spencer, M, Nasir, T, Campbell, M, Harrison, M & Wallace, R 2015, *Indigenous Governance and Leadership Development Project: Final Report and Evaluation*, Darwin, Charles Darwin University.

Chudakova, T 2017, 'Caring for Strangers: Aging, Traditional Medicine, and Collective Self-care in Post-socialist Russia', *Medical Anthropology Quarterly*, vol. 31, no. 1, pp. 78-96.

Clark, M & May, S (eds) 2013, *Macassan History and Heritage: Journeys, Encounters and Influences*, Canberra, ANU e-Press.

Clarke, A, Mamo, L, Fosket, JR, Fishman, JR & Shim, JK (eds) 2010, *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, Durham and London, Duke University Press.

Clarkson, C, Jacobs, Z, Marwick, B, Fullagar, R, Wallis, L, Smith, M, Roberts, RG, Hayes, E, Lowe, K, Carah, X, Florin, AS, McNeil, JS, Cox, D, Arnold, LJ, Hua, Q, Huntley, J, Brand, HEA, Manne, T, Fairbairn, A, Shulmeister, J, Lyle, L, Salinas, M, Page, M, Connell, K, Park, G, Norman, K, Murphy, T & Pardoe, C 2017, 'Human occupation of northern Australia by 65,000 years ago', *Nature*, vol. 547, no. 7663, pp. 306-310.

Clifford, J 1992, 'Traveling Cultures', in L Grossberg, C Nelson & P Treichler (eds), *Cultural Studies*, New York and London, Routledge, pp. 96-116.

Colles, S & Maypilama, E 2014, *Food and Health Communication Across Cultures: Considerations for Health Professionals Working With Remote Aboriginal Communities*, Darwin, Menzies School of Health Research.

Commonwealth Grants Commission 2016, *Changes in State Budgets 2000-01 to 2014-15*, Canberra, Australian Government.

Corn, A 2009, *Reflections and Voices: Exploring the music of Yothu Yindi with Mandawuy Yunupiŋu*, Sydney, Sydney University Press.

Coulehan, K 1995, *Sitting down in Darwin: Yolngu women and family life*, PhD thesis, Northern Territory University.

Coulehan, K 1996, '"Keeping Company" in Sickness and in Health: Yolngu from Northeast Arnhem Land and Medical Related Transience and Migration to Darwin', in G Robinson (ed.), *Aboriginal Health: Social and Cultural Transitions. Proceedings of a Conference at the Northern Territory University Darwin 29-31 September 1995*, Darwin, NTU Press.

Council of Australian Governments & Coalition of Aboriginal and Torres Strait Islander Peak Organisations 2020, *National Agreement on Closing the Gap*, Canberra, Australian Government.

Cubellis, L 2020, 'Gestures of care and recognition: An introduction', *Cultural Anthropology*, vol. 35, no. 1, pp. 1-5.

Cunneen, C & Libesman, T 1995, *Indigenous People and the Law in Australia*, Sydney, Butterworths.

Da Roit, B & De Klerk, J 2014, 'Heaviness, intensity, and intimacy: Dutch elder care in the context of retrenchment of the welfare state', *Medicine Anthropology Theory*, vol. 1, no. 1, pp. 1-12.

Daly, A & Smith, D 1999, *Indigenous household demography and socioeconomic status: the policy implications of 1996 Census data*, CAEPR Discussion Paper No. 181, Centre for Aboriginal Economic Policy Research, Australian National University Canberra.

Darwin Community Legal Service & Central Australian Womens Legal Service 2018, *Submission to the Economic Policy Scrutiny Committee, Residential Tenancies Amendment Bill 2018*, Darwin, Darwin Community Legal Service.

Das, V 2015, *Affliction: Health, Disease, Poverty*, New York, Fordham University Press.

Davidson, P & Whiteford, P 2012, *An Overview of Australia's System of Income and Employment Assistance for the Unemployed*, OECD Social, Employment and Migration Working Papers No. 129, Organisation for Economic Cooperation and Development, Paris.

Dawson, A & Goodwin-Hawkins, B 2018, 'Moralities of care in later life', *The Australian Journal of Anthropology*, vol. 29, no. 2, pp. 141-145.

Day, W 2000, *Aboriginal Fringe Dwellers in Darwin, Australia: Cultural Persistence or a Culture of Resistance?*, PhD thesis, University of Western Australia.

Day, W 2007, 'The Wheel Turns for Homeless Indigenous People in Darwin, 1967–2007', *Parity*, vol. 20, no. 10, p. 16.

Deger, J 2016, 'Thick Photography', *Journal of Material Culture*, vol. 21, no. 1, pp. 111-132.

Devitt, J & McMasters, A 1998, *Living on Medicine: A Cultural Study of End-stage Renal Disease among Aboriginal People*, Alice Springs, IAD Press.

Devlin, B, Disbray, S & Devlin, N (eds) 2017, *History of Bilingual Education in the Northern Territory: People, Programs and Policies*, Singapore, Springer.

Dewar, M 1992, *The 'Black War' in Arnhem Land: missionaries and the Yolngu 1908-1940*, Darwin, North Australia Research Unit, Australian National University

Dockery, A & Colquhoun, S 2012, *Mobility of Aboriginal and Torres Strait Islander people: A literature review*, Cooperative Research Centre for Remote Economic Participation Working Paper CW004, Ninti One Limited, Alice Springs.

Dockery, M, Ong, R, Colquhoun, S, Li, J & Kendall, G 2013, *Housing and children's development and wellbeing: evidence from Australian data*, AHURI Final Report No. 201, Melbourne, Australian Housing and Urban Research Institute.

Duclos, V & Criado, TS 2019, 'Care in Trouble: Ecologies of Support from Below and Beyond', *Medical Anthropology Quarterly*, vol. 34, no. 2, pp. 153-173.

Dunholt, P & Langstrup, H 2012, 'Medication as Infrastructure: Decentring Self-care', *Culture Unbound: Journal of Current Cultural Research*, vol. 4, pp. 513-532.

Dussart, F 2010, '"It Is Hard to Be Sick Now": Diabetes and the Reconstruction of Indigenous Sociality', *Anthropologica*, vol. 52, no. 1, pp. 77-87.

Egan, T 1996, *Justice All Their Own: The Caledon Bay and Woodah Island Killings, 1932–1933*, Melbourne, Melbourne University Press.

Elkin, AP 1951, 'Reaction and Interaction: A Food Gathering People and European Settlement in Australia', *American Anthropologist*, vol. 53, no. 2, pp. 164-186.

Ellis, K 2005, 'Dependency, justice and the ethic of care', in H Dean (ed.), *The Ethics of Welfare: Human rights, dependency and responsibility*, Bristol, The Poilcy Press, pp. 29-48.

Esping-Andersen, G 1990, *The Three Worlds of Welfare Capitalism*, Princeton, Princeton University Press.

Faier, L & Rofel, L 2014, 'Ethnographies of Encounter', *Annual Review of Anthropology*, vol. 43, pp. 363-377.

Fantin, S 2003, 'Yolngu Cultural Imperatives and Housing Design', in P Memmott & C Chambers (eds), *TAKE 2: Housing Design in Indigenous Australia*, Canberra, The Royal Australian Institute of Architects, pp. 72-79.

Farmer, P 2003, *Pathologies of Power: Health, human rights and the new war on the poor*, Berkeley, Los Angeles and London, University of California Press.

Fassin, D 2009, 'Another Politics of Life is Possible', *Theory, Culture & Society*, vol. 26, no. 5, pp. 44-60.

Fassin, D 2012, 'Introduction: Towards a Critical Moral Anthropology', in D Fassin (ed.), *A Companion to Moral Anthropology*, West Sussex, Wiley Blackwell, pp. 1-18.

Feder Kittay, E & Feder, E (eds) 2002, *The Subject of Care: Feminist Perspectives on Dependency*, London, Rowman and Littlefield Publishers.

Feldman, I & Ticktin, M 2010, 'Introduction', in I Feldman & M Ticktin (eds), *In the Name of Humanity: The Government of Threat and Care*, Durham and London, Duke University Press, pp. 1-26.

Fennell, C 2015, *Last project standing: civics and sympathy in post-welfare Chicago*, Minneapolis, University of Minnesota Press.

Ferguson, J 2013, 'Declarations of dependence: labour, personhood, and welfare in southern Africa', *Journal of the Royal Anthropological Institute*, vol. 19, pp. 223-242.

Ferguson, M, Brown, C, Georga, C, Miles, E, Wilson, A & Brimblecombe, J 2017, 'Traditional food availability and consumption in remote Aboriginal communities in the Northern Territory, Australia', *Australian and New Zealand Journal of Public Health*, vol. 41, no. 3, pp. 294-298.

Fine, M & Glendinning, C 2005, 'Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'', *Aging and Society*, vol. 25, pp. 601–621.

Fine, MD 2007a, *A Caring Society? Care and the Dilemmas of Human Service in the Twenty-First Century*, New York, Palgrave Macmillan.

Fine, MD 2007b, 'Risk, Care and the New Logic of Global Capitalism', in MD Fine (ed.), *A Caring Society? Care and the Dilemmas of Human Service in the Twenty-First Century*, New York, Palgrave Macmillan, pp. 199-225.

Fineman, M 2004, *The Autonomy Myth: A Theory of Dependency*, New York and London, The New Press.

Finlayson, J 1989, 'Welfare incomes and Aboriginal gender relations', in J Altman (ed.), *Emergent Inequalities in Aboriginal Australia, Oceania Monograph*, Sydney, University of Sydney, pp. 95-118.

Finlayson, J 1991, *Don't Depend on Me: Autonomy and dependence in an Aboriginal community in North Queensland*, PhD thesis, Australian National University.

Fisher, D 2015, 'An Urban Frontier: Respatialising Government in Remote Northern Australia', *Cultural Anthropology*, vol. 30, no. 1, pp. 139-166.

Fisher, D 2016, *The Voice and its Doubles: Media and Music in Northern Australia*, Durham and London, Duke Universtiy Press.

Flint, J 2003, 'Housing and ethopolitics: constructing identities of active consumption and responsible community', *Economy and Society*, vol. 32, no. 4, pp. 611-629.

Flint, J 2004, 'The responsible tenant: housing governance and the politics of behaviour', *Housing Studies*, vol. 19, no. 6, pp. 893-909.

Folds, R 2001, *Crossed Purposes: The Pintupi and Australia's Indigenous Policy*, Sydney, UNSW Press.

Fowkes, L 2019, *The application of income support obligations and penalties to remote Indigenous Australians, 2013 - 18*, CAEPR Working Paper No. 126, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Franklin, S & McKinnon, S (eds) 2001, *Relative Values: Reconfiguring Kinship Studies*, Durham and London, Duke University Press.

Gale, F 1981, 'Adjustment of migrants in cities: Aborigines in Adelaide, Australia', in GW Jones & H Richter (eds), *Population mobility and development: Southeast Asia and the Pacific*, Canberra, Development Studies Centre, Australian National University, pp. 283-303.

Garcia, A 2010, *The Pastoral Clinic: Addiction and Dispossession Along the Rio Grande*, Berkeley, Los Angeles and London, University of California Press.

Garnett, S, Coe, K, Golebiowska, K, Walsh, H, Zander, K, Guthridge, S, Li, S & Malyon, R 2008, *Attracting and Keeping Nursing Professionals in an Environment of Chronic Labour Shortage: A Study of Mobility among Nurses and Midwives in the Northern Territory of Australia*, Darwin, Charles Darwin University Press.

Geertz, C 1973, 'Thick Description: Toward an Interpretive Theory of Culture', in C Geertz (ed.), *The Interpretation of Cultures: Selected Essays*, New York, Basic Books, pp. 3-30.

Gerritsen, R 2010, 'A post-colonial model for North Australia political economy: The case of the NT', in R Gerritsen (ed.), *North Australian political economy : Issues and agendas*, Darwin, Charles Darwin University Press, pp. 18-40.

Gesler, W 1992, 'Therapeutic Landscapes: Medical Issues in Light of the New Cultural Geography', *Social science and medicine*, vol. 34, no. 7, pp. 735-746.

Gesler, W 2005, 'Therapeutic landscapes: An evolving theme', *Health and Place*, vol. 11, pp. 295–297.

Giddens, A 1990, *The Consequences of Modernity*, Cambridge, Polity Press.

Gifford, S 1986, 'The Meaning of Lumps: A Case Study of the Ambiguities of Risk', in C Janes (ed.), *Anthropology and Epidemiology: Interdiscipinary Approaches to the Study of Health and Disease*, Dordrecht, D. Reidel Publishing Company, pp. 213-246.

Gilligan, C 1982, *In a Different Voice: Psychological Theory and Women's Development*, Cambridge and London, Harvard University Press.

Godwin Thompson, J 2014, *'Livin' the DJ Way': Aboriginal housing and health in Dajarra*, PhD thesis, University of Queensland.

Goodin, R 2002, 'Structures of Mutual Obligation', *Journal of Social Policy*, vol. 31, no. 4, pp. 579-596.

Gorham, G 2000, *Tiwi Dialysis Centre: The Economic and Social Repurcussions of Client Relocation* Darwin, Nightcliff Renal Unit.

Gorham, G 2001, *Prevention and Treatment Options for Renal Disease in the Northern Territory (with particular reference to the Barkly Region)*, Darwin, The Cooperative Research Centre for Aboriginal and Tropical Health and the Northern Territory Department of Health and Community Services.

Gorham, G, Cass, A, Howard, K & Evans, K 2016, *Central Australia Renal Study Technical Report Update*, Menzies School of Health Research, prepared for the Australian Government Department of Health, Darwin.

Gorham, G, Howard, K, Togni, S, Lawton, P, Hughes, J, Majoni, S, Brown, S, Barnes, S & Cass, A 2017, 'Economic and quality of care evaluation of dialysis service models in remote Australia: protocol for a mixed methods study', *BMC Health Services Research*, vol. 17, no. 320.

Gorham, G, Howard, K, Zhao, Y, Ahmed, A, Lawton, P, Sajiv, C, Majoni, W, Wood, P, Conlon, T, Signal, S, Robinson, S, Brown, S & Cass, A 2019, 'Cost of dialysis therapies in rural and remote Australia – a micro-costing analysis', *BMC Nephrology*, vol. 20, no. 231.

Gorham, G, Majoni, S, Lawton, P, Brown, S, Dube, B, Conlon, T, Sajiv, C, Wood, P, Signal, S & Cass, A 2018, 'Interesting times —evolution of dialysis in Australia's Northern Territory (1980–2014)', *Renal Society of Australasia Journal*, vol. 14, no. 3, pp. 108-116.

Gorham, G, Wagner, L & Jose, M 2005, 'The Northern Territory's Remote and Community-based Haemodialysis Program: Interesting Times', *Renal Society of Australasia Journal*, vol. 1, no. 2, pp. 59-63.

Graeber, D 2001, *Toward An Anthropological Theory of Value: The False Coin of Our Own Dreams*, New York, Palgrave Macmillam.

Gregory, C & Altman, J (eds) 2018, *The Quest for the Good Life in Precarious Times: Ethnographic Perspectives on the Domestic Moral Economy*, Canberra, ANU Press.

Guyer, J 2012, 'Obligation, binding, debt and responsibility: provocations about temporality from two new sources', *Social Anthropology*, vol. 20, no. 4, pp. 491-501.

Habibis, D, Birdsall-Jones, C, Dunbar, T, Scrimgeour, M, Taylor, E & Nethercote, M 2011, *Improving housing responses to Indigenous patterns of temporary mobility*, AHURI Final Report No. 162, Australian Housing and Urban Research Institute, Melbourne.

Habibis, D, Memmott, P, Phillips, R, Go-Sam, C, Keys, C & Moran, M 2013, *Housing conditionality, Indigenous lifeworlds and policy outcomes: towards a model for culturally responsive housing provision*, AHURI Final Report No. 212, Australian Housing and Urban Research Institute, Melbourne.

Hage, G 2014, 'On stuckedness: The critique of crisis and the crisis of critique', in G Hage (ed.), *Alter-Politics: Critical Anthropology and the Radical Imagination*, Melbourne, Melbourne University Press, pp. 31-39.

Hage, G & Eckersley, R 2012, 'Introduction', in G Hage & R Eckersley (eds), *Responsibility*, Melbourne, Melbourne University Press, pp. 6-19.

Hamilton, A 1981, *Nature and Nurture: Aboriginal child-rearing in north-central Arnhem Land*, Canberra, Australian Institute of Aboriginal Studies.

Han, C 2012, *Life in debt: times of care and violence in neoliberal Chile*, Berkeley, University of California Press.

Harkins, J 1996, 'Linguistic and Cultural Differences in Concepts of Shame', in D Parker, R Dalziell & I Wright (eds), *Shame and the Modern Self*, Melbourne, Australian Scholarly Publishing, pp. 84-96.

Harris, SG 1987, 'Yolngu Rules of Interpersonal Communication', in WH Edwards (ed.), *Traditional Aboriginal Society: A Reader*, South Melbourne, Macmillan, pp. 1-9.

Heil, D 2006, 'Shifting expectations of treatment: from 'patient as individual' to 'patient as social person'', *Australian Aboriginal Studies*, vol. 2, pp. 98-110.

Heil, D & Macdonald, G 2008, ''Tomorrow comes when tomorrow comes': Managing Aboriginal Health within an Ontology of Life-as-Contingent', *Oceania*, vol. 78, no. 3, pp. 299-319.

Heinemann, LL 2015, 'Accommodating care: Transplant caregiving and the melding of health care with home life in the United States', *Medicine Anthropology Theory*, vol. 2, no. 1, pp. 32–56.

Hochschild, AR 1983, *The Managed Heart: commercialization of human feeling* Berkeley, University of California Press.

Holmes, C & McRae-Williams, E 2008, *An investigation into the influx of Indigenous 'visitors' to Darwin's Long Grass from remote NT communities – Phase 2*, Monograph Series No. 33, Larrakia Nation Aboriginal Corporation, Darwin.

Honkasalo, ML 2006, 'Fragilities in life and death: Engaging in uncertainty in modern society', *Health, Risk and Society*, vol. 8, no. 1, pp. 27-41.

Hoppe, S 2020, 'The Other Within Oneself: Understanding Care for a Family Member with Early-Onset Dementia Through the Lens of Dividuality', *Ethos*, vol. 48, no. 2, pp. 231–249.

Hopper, K 2001, 'Commentary: On the Transformation of the Moral Economy of Care', *Culture, Medicine and Psychiatry*, vol. 25, no. 4, pp. 473-484.

House of Representatives Standing Committee on Indigenous Affairs 2020, *Report on food pricing and food security in remote Indigenous communities*, Canberra, TPotCo Australia.

Hoy, W 1998, 'Renal disease as a metaphor: towards a more integrated view of Aboriginal health', *Clinical and Experimental Pharmacology and Physiology*, vol. 25, pp. 1038-1042.

Hoy, W, Vanbuynder, P, Mathews, J, Pugsley, D & Wang, Z 2001, 'Renal disease and the environment: lessons from Aboriginal Australia', *Nephrology*, vol. 5, pp. 19-24.

Huang, S 2015, *Urbanizing carescapes of Hong Kong: two systems, one city*, Lanham, Lexington Books.

Hughes, H 2007, *Lands of Shame: Aboriginal and Torres Strait Islander 'Homelands' in Transition*, St Leonards, Centre for Independent Studies.

Hughes, J, Dembski, L, Kerrigan, V, Majoni, S, Lawton, P & Cass, A 2018, 'Gathering Perspectives - Finding Solutions for Chronic and End Stage Kidney Disease', *Nephrology*, vol. 23s, pp. 5-13.

Human Capital Alliance 2009, *Aboriginal Health Worker Professional Review: Final Report*, Darwin, Northern Territory Department of Health and Families.

Jackson, S & Jones, J (eds) 1998, *Contemporary Feminist Theories*, Edinburgh, Edinburgh University Press.

Jebb, MA 2002, *Blood, Sweat and Welfare: A history of white bosses and Aboriginal pastoral workers*, Perth, University of Western Australia Press.

Jolliffe, P & Worland, S 2018, 'Honouring the elders: The common good among Karen communities - a multi-sited ethnography', *The Australian Journal of Anthropology*, vol. 29, no. 2, pp. 158-170.

Jordan, K (ed.) 2016, *Better Than Welfare? Work and Livelihoods for Indigenous Australians After CDEP*, Canberra, ANU e-Press.

Katz, MB 1989, *The Undeserving Poor: From the war on poverty to the war on welfare*, New York, Pantheon Books.

Kaufert, P & O'Neil, J 1993, 'Analysis of a Dialogue on Risks in Childbirth: Clinicians, Epidemiologists, and Inuit Women', in S Lindenbaum & M Lock (eds), *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life*, Berkeley, University of California Press, pp. 32-54.

Kaufman, SR 2003, 'Hidden places, uncommon persons', *Social science and medicine*, vol. 56, pp. 2249–2261.

Kaufman, SR & Morgan, LM 2005, 'The Anthropology of the Beginnings and Ends of Life', *Annual Review of Anthropology*, vol. 34, pp. 317-341.

Kearney, A 2017, *Violence in Place, Cultural and Environmental Wounding*, Oxon and New York, Routledge.

Keen, I 1995, 'Metaphor and metalanguage: "groups" in northeast Arnhem Land', *American Ethnologist*, vol. 22, no. 3, pp. 502-527.

Keen, I 2004, *Aboriginal Economy and Society: Australia at the Threshold of Colonisation*, Melbourne, Oxford University Press.

Khanal, N, Lawton, P, Cass, A & McDonald, S 2018, 'Disparity of access to kidney transplantation by Indigenous and non-Indigenous Australians', *Medical Journal of Australia*, vol. 209, no. 6, pp. 261-266.

Kim, ED & Parekh, RH 2015, 'Calcium and Sudden Cardiac Death in End-Stage Renal Disease', *Seminars in Dialysis*, vol. 28, no. 6, pp. 624-635.

Klang, B & Clyne, N 1997, ' Well-being and Functional Ability in Uraemic Patients Before and After Having Started Dialysis Treatment', *Scandinavian Journal of Caring Science*, vol. 11, pp. 159-166.

Klein, E 2016, 'Neoliberal subjectivities and the behavioural focus on income management', *Australian Journal of Social Issues*, vol. 51, no. 4, pp. 503-523.

Kleinman, A 1988, *The Illness Narratives: Suffering, Healing, and the Human Condition*, New York, Basic Books.

Kleinman, A 2012, 'Caregiving as moral experience', *The Lancet*, vol. 380, no. 9853.

Kleinman, A 2013, 'From Illness as Culture to Caregiving as Moral Experience', *New England Journal of Medicine*, vol. 368, no. 15, pp. 1376-1377.

Kleinman, A, Das, V & Lock, M 1997, 'Introduction', in A Kleinman, V Das & M Lock (eds), *Social Suffering*, Berkeley, University of California Press, pp. ix-xxvii.

Kovesdy, CP 2016, 'Malnutrition in Dialysis Patients—The Need for Intervention Despite Uncertain Benefits', *Seminars in Dialysis*, vol. 29, no. 1, pp. 28–34.

Kowal, E 2008, 'The Politics of the Gap: Indigenous Australians, Liberal Multiculturalism, and the End of the Self-Determination Era', *American Anthropologist*, vol. 110, no. 3, pp. 338-348.

Kowal, E 2015, *Trapped in The Gap: Doing Good in Indigenous Australia*, New York and Oxford, Berghahn Books.

Kral, I 2017, *Submission to the Senate Finance and Public Administration Committee Inquiry into the appropriateness and effectiveness of the objectives, design, implementation and evaluation of the Community Development Program (CDP)*, Canberra, Parliament of Australia.

Kwok, N 2005, *'Owning' a marginal identity: shame and resistance in an Aboriginal community*, PhD thesis, The Australian National University.

Kwok, N 2012, 'Shame and the Embodiment of Boundaries', *Oceania*, vol. 82, no. 1, pp. 28-44.

Kyeong Seo, B 2016, 'Patient waiting: care as a gift and debt in the Thai healthcare system', *Journal of the Royal Anthropological Institute*, vol. 22, no. 2, pp. 279-295.

Lahn, J, Puszka, S, Lawton, P, Dinku, Y, Nichols, N & Markham, F 2020, *Beyond parity in Aboriginal and Torres Strait Islander health workforce planning: Achieving equity through needs-based and strengths-based approaches*, commissioned report for the National Health Leadership Forum, Centre for Aboriginal Economic Policy Research, Canberra.

Larrakia Nation Aboriginal Corporation 2019, *Larrakia Rangers*, Accessed 17 April 2019 http://larrakia.com/services/larrakia-rangers/.

Lawton, P 2017, 'Letter to editor: Response to An Expanded Nationwide View of Chronic Kidney Disease in Aboriginal Australians', *Nephrology*, vol. 22, no. 182.

Lawton, P 2018, 'Not all doctors agree my patient deserved his kidney transplant. They're wrong.', *ABC News*, 11 January, Accessed 2 July 2020 https://www.abc.net.au/news/2018-01-11/should-my-aboriginal-patient-have-received-a-kidney-transplant/9280454.

Laycock, A, Walker, D, Harrison, N & Brands, J 2011, *Researching Indigenous health: a practical guide for researchers*, Carlton South, The Lowitja Institute.

Lea, T 2006, 'Cars, Corporations, Ceremonies and Cash: Hidden Co-dependencies in Australia's North', in T Lea, E Kowal & G Cowlishaw (eds), *Moving Anthropology: Critical Indigenous Studies*, Darwin, Charles Darwin University Press, pp. 37-53.

Lea, T 2008, *Bureaucrats and Bleeding Hearts: Indigenous Health in Northern Australia*, Sydney, UNSW Press.

Lea, T 2014, *Darwin*, Sydney, NewSouth.

Lea, T, Young, M, Markham, F, Holmes, C & Doran, B 2012, 'Being Moved (On): The Biopolitics of Walking in Australia's Frontier Towns', *Radical History Review*, vol. 114, pp. 139-163.

Li, J, Brown, L, La, HN, Miranti, R & Vidyattama, Y 2019, *Inequalities In Standards of Living: Evidence for Improved Income Support for People with Disability*, NATSEM Institute for Governance and Policy Analysis, University of Canberra. Report commissioned by the Australia Federation of Disability Organisations, Canberra.

Lock, M & Gordon, D (eds) 1988, *Biomedicine Examined*, Dordrecht, Boston and London, Kluwer Academic Publishers.

Loff, B & Cordner, S 1998, 'Aboriginal people trade land claim for dialysis', *The Lancet*, vol. 352, no. 9138, p. 1451.

Long, J 1970, *Aboriginal Settlements: A Survey of Institutional Communities in Eastern Australia*, Canberra, Australian National University Press.

Long, S, Memmott, P & Seelig, T 2007, *An audit and review of Australian Indigenous housing research*, AHURI Final Report No. 102, Australian Housing and Urban Research Institute, Brisbane.

Lowe, M, Kerridge, I & Mitchell, K 1995, ''These sorts of people don't do very well': race and allocation of health care resources', *Journal of Medical Ethics*, vol. 21, pp. 356-360.

Lowell, A, Brown, I, Marrnganyin, B, Flack, M, Christie, M, Snelling, P & Cass, A 2005, *Sharing the True Stories: Improving Communication between Health Staff and Aboriginal Patients*, Darwin, Cooperative Research Centre for Aboriginal Health.

Macdonald, G 2000, 'Economies and Personhood: Demand Sharing among the Wiradjuri of New South Wales', in G Wenzel, G Hovelsrud-Broda & N Kishigami (eds), *The Social Economy of Sharing: Resource Allocation and Modern Hunter-Gatherers*, Osaka, National Museum of Ethnology, pp. 87-111.

Macdonald, G 2018, 'The Role of Allocative Power and its Diminution in the Constitution and Violation of Wiradjuri Personhood', in D Austin-Broos & F Merlan (eds), *People and Change in Indigenous Australia*, Honolulu, University of Hawai'i Press, pp. 108-126.

Macdonald, G & Mears, J (eds) 2019, *Dementia as Social Experience: Valuing Life and Care*, Abingdon, Routledge.

Macdonald, G, Mears, J & Naderbagi, A 2019, 'Reframing dementia: the social imperative', in G Macdonald & J Mears (eds), *Dementia as Social Experience: Valuing Life and Care*, Abingdon, Routledge.

Macknight, CC 1976, *The Voyage to Marege'*, Melbourne, Melbourne University Press.

Magowan, F 2001a, 'Syncretism or Synchonicity? Remapping the Yolngu Feel of Place', *Australian Journal of Anthropology*, vol. 12, no. 3, pp. 275-290.

Magowan, F 2001b, 'Waves of Knowing: Polymorphism and Co-Substantive Essences in Yolngu Sea Cosmology', *Australian Journal of Indigenous Education*, vol. 29, no. 1, pp. 22-35.

Magowan, F 2018, 'Cycles of Integration and Fragmentation: Changing Yolngu–Balanda Sentiments of the 'Good Life' in Northern Australia', in C Gregory & J Altman (eds), *The Quest for the Good Life in Precarious Times: Ethnographic Perspectives on the Domestic Moral Economy*, Canberra, ANU Press, pp. 139-162.

Mahmood, S 2001, ' Feminist Theory, Embodiment, and the Docile Agent: Some Reflections on the Egyptian Islamic Revival', *Cultural Anthropology*, vol. 16, no. 2, pp. 202-236.

Majoni, S, Hughes, J, Heron, B & Currie, B 2018, 'Trimethoprim+Sulfamethoxazole Reduces Rates of Melioidosis in High-Risk Hemodialysis Patients', *Kidney International Reports*, vol. 3, no. 1, pp. 160-167.

Malkii, L 1995, 'Refugees and Exile: From "Refugee Studies" to the National Order of Things', *Annual Review of Anthropology*, vol. 24, pp. 495-523.

Manderson, L & Smith-Morris, C (eds) 2010, *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, New Jersey, Rutgers University Press.

Marcus, GE 1995, 'Ethnography in/of the world system: The emergence of multi-sited ethnography', *Annual Review of Anthropology*, vol. 24, pp. 95-117.

Marika, R 1999, 'The 1998 Wentworth Lecture', *Australian Aboriginal Studies*, vol. 3, pp. 3-9.

Marika, R, Ngurruwutthun, D & White, L 1992, 'Always together, yaka gana: Participatory research as part of the development of a Yolngu education', *Convergence*, vol. 25, no. 1, pp. 23-41.

Marika, R, Yunupingu, Y, Marika-Mununggiritj, R & Muller, S 2009, 'Leaching the poison – The importance of process and partnership in working with Yolngu', *Journal of Rural Studies*, vol. 25, pp. 404-413.

Marika-Mununggiritj, R 1991, 'Some notes on principles for Aboriginal pedagogy', *Ngoonjook: A Journal of Australian Indigenous Studies*, vol. 6, pp. 33-34.

Markham, F & Doran, B 2015, 'Equity, discrimination and remote policy: Investigating the centralization of remote service delivery in the Northern Territory', *Applied Geography*, vol. 58, pp. 105-115.

Marks, R 2018, 'Held to account', *The Monthly*, March, Black Inc., Melbourne.

Markus, A 1990, *Governing Savages*, Sydney, Allen and Unwin.

Marley, J, Dent, H, Wearne, M, Fitzclarence, C, Nelson, C, Siu, K, Warr, K & Atkinson, D 2010, 'Haemodialysis outcomes of Aboriginal and Torres Strait Islander patients of remote Kimberley region origin', *Medical Journal of Australia*, vol. 193, no. 9, pp. 516-520.

Marsland, R & Prince, R 2012, 'What Is Life Worth? Exploring Biomedical Interventions, Survival, and the Politics of Life', *Medical Anthropology Quarterly*, vol. 26, no. 4, pp. 453-469.

Martin, DF 2011, 'Policy Alchemy and the Magical Transformation of Aboriginal Society', in Y Musharbash & M Barber (eds), *Ethnography and the Production of Anthropological Knowledge: Essays in Honour of Nicholas Peterson*, Canberra, ANU ePress, pp. 201-215.

Martin, K 2003, 'Ways of knowing, being and doing: A theoretical framework and methods for indigenous and indigenist re-search', *Journal of Australian Studies*, vol. 27, no. 76, pp. 203-214.

Mauss, M 1954, *The Gift: Forms and functions of exchange in archaic societies*, New York, Norton.

Maypilama, E, Garŋgalkpuy, J, Christie, M, Greatorex, J & Grace, J 2004, *Yolŋu Longgrassers on Larrakia Land*, Darwin, Charles Darwin University.

McCluskey, MT 2002, 'Subsidized Lives and the Ideology of Efficiency', in E Feder Kittay & E Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency*, London, Rowman and Littlefield Publishers, pp. 115-137.

McCoy, B 2008, *Holding Men: Kanyirninpa and the health of Aboriginal men*, Canberra, Aboriginal Studies Press.

McDonald, S & Russ, GP 2002, 'Survival of recipients of cadaveric kidney transplants compared with those receiving dialysis treatment in Australia and New Zealand, 1991–2001', *Nephrology Dialysis Transplantation*, vol. 17, no. 12, pp. 2212–2219.

McDowell, L, Ray, K, Perrons, D, Fagan, C & Ward, K 2005, 'Women's paid work and moral economies of care', *Social and Cultural Geography*, vol. 6, no. 2, pp. 219-235.

McGrath, A 1987, *Born in the Cattle: Aborigines in Cattle Country*, Sydney, Allen and Unwin.

McKenzie, HJ, McHugh, C & McKay, FH 2016, 'Life on newstart allowance: a new reality for low-income single mothers', *Journal of Family Studies*, vol. 25, no. 1, pp. 18-33.

McMillan, A 1988, *Strict Rules: The Blackfella - Whitefella Tour*, Darwin, Niblock Publishing.

Mee, KJ 2009, 'A space to care, a space of care: public housing, belonging, and care in inner Newcastle, Australia', *Environment and Planning A: Economy and Space*, vol. 41, pp. 842-858.

Meiu, GP 2015, ''Beach-Boy Elders' and 'Young Big-Men': Subverting the Temporalities of Ageing in Kenya's Ethno-Erotic Economies', *Ethnos*, vol. 80, no. 4, pp. 472-496.

Memmott, P & Chambers, C (eds) 2003, *TAKE 2: Housing Design in Indigenous Australia*, Canberra, The Royal Australian Institute of Architects.

Memmott, P, Long, S & Thomson, L 2006, *Indigenous mobility in rural and remote Australia*, AHURI Final Report No. 90, Australian Housing and Urban Research Institute, Brisbane.

Merlan, F 1991, 'Women, Productive Roles, and Monetisation of the 'Service Mode' in Aboriginal Australia: Perspectives from Katherine, Northern Territory', *Australian Journal of Anthropology*, vol. 2, no. 3, pp. 259-292.

Milligan, C 2003, 'Location or dis-location? Towards a conceptualization of people and place in the care- giving experience`', *Social and Cultural Geography*, vol. 4, no. 4, pp. 455-470.

Milligan, C & Wiles, J 2010, 'Landscapes of care', *Progress in Human Geography*, vol. 34, no. 6, pp. 736-754.

Milligan, V, Phillips, R, Easthope, H, Liu, E & Memmott, P 2011, *Urban social housing for Aboriginal people and Torres Strait Islanders: respecting culture and adapting services*, AHURI Final Report No. 172, Australian Housing and Urban Research Institute, Melbourne.

Mol, A 2008, *The Logic of Care: Health and the problem of patient choice*, London and New York, Routledge.

Mol, A, Moser, I & Pols, J 2010, 'Care: putting practice into theory', in A Mol, I Moser & J Pols (eds), *Care in Practice: On Tinkering in Clinics, Homes and Farms*, Bielefeld, Transcript, pp. 7-26.

Moreton-Robinson, A 2000, *Talkin' Up to the White Woman: Aboriginal women and feminism* St Lucia, University of Queensland Press.

Morphy, F 2007a, 'The language of governance in a cross-cultural cultural context: what can and can't be translated', *Ngiya: Talk the Law*, vol. 1, pp. 93-102.

Morphy, F 2007b, 'Uncontained subjects: Population and household in remote Aboriginal Australia', *Journal of Population Research*, vol. 24, no. 2, pp. 163-184.

Morphy, F 2010, '(Im)mobility: Regional Population Structures in Aboriginal Australia', *The Australian Journal of Social Issues*, vol. 45, no. 3, pp. 363-382.

Morphy, F & Morphy, H 2012, '"Soon We Will Be Spending All Our Time at Funerals": Yolngu Mortuary Rituals in an Epoch of Constant Change', in S Howell & A Talle (eds), *Returns to the Field: Multitemporal Research and Contemporary Anthropology*, Bloomington and Indianapolis, Indiana University Press, pp. 49-72.

Morphy, F & Morphy, H 2013, 'Anthropological Theory and Government Policy in Australia's Northern Territory: The Hegemony of the "Mainstream"', *American Anthropologist*, vol. 115, no. 2, pp. 174-187.

Morphy, H 1991, *Ancestral Connections: Art and an Aboriginal System of Knowledge*, Chicago and London, University of Chicago Press.

Morphy, H 1995, 'Death, Exchange and the Reproduction of Yolngu Society', in F Merlan, J Morton & A Rumsey (eds), *Scholar and Sceptic: Australian Aboriginal Studies in Honour of LR Hiatt*, Canberra, Aboriginal Studies Press, pp. 123-150.

Morphy, H 2005, 'Mutual Conversion? The Methodist Church and the Yolŋu, with particular reference to Yirrkala', *Humanities Research*, vol. 12, no. 1, pp. 41-53.

Morphy, H 2009, 'Acting in a community: Art and social cohesion in Indigenous Australia', *Humanities Research*, vol. 15, no. 2, pp. 115-131.

Morphy, H 2016, 'Extended lives in global spaces: the anthropology of Yolngu pre-burial ceremonies', *Journal of the Royal Anthropological Institute*, vol. 22, no. 2, pp. 332-355.

Morphy, H & Morphy, F 2006, 'Tasting the Waters: Discriminating Identities in the Waters of Blue Mud Bay', *Journal of Material Culture*, vol. 11, no. 1/2, pp. 67-85.

Morris, A & Wilson, S 2014, 'Struggling on the Newstart unemployment benefit in Australia: The experience of a neoliberal form of employment assistance', *The Economic and Labour Relations Review*, vol. 25, no. 2, pp. 202-221.

Morrison, S 2018, 'Transcript of new Prime Minister Scott Morrison's first press conference', *The Financial Review*, 24 August, Accessed 11 March 2020 https://www.afr.com/politics/transcript-of-new-prime-minister-scott-morrisons-first-press-conference-20180824-h14h1a.

Muehlebach, A 2007, *The Moral Neoliberal: Welfare State and Ethical Citizenship in Contemporary Italy*, PhD thesis, University of Chicago.

Muehlebach, A 2012, *The Moral Neoliberal: Welfare and citizenship in Italy*, London, University of Chicago Press.

Murray Li, T 2014, *Land's End: Capitalist Relations on an Indigenous Frontier*, Durham and London, Duke University Press.

Musharbash, Y 2008, *Yuendumu everyday: contemporary life in remote Aboriginal Australia*, Canberra, Aboriginal Studies Press.

Myers, F 1986, *Pintupi Country, Pintupi Self: Sentiment, Place, and Politics among Western Desert Aborigines*, Berkeley, Los Angeles and London, University of California Press.

Myers, F & Peterson, N 2016, 'The origins and history of outstations as Aboriginal life projects', in N Peterson & F Myers (eds), *Experiments in self-determination: Histories of the outstation movement in Australia*, Canberra, ANU Press, pp. 1-24.

Nagel, T, Robinson, G, Condon, J & Trauer, T 2009, 'Approach to treatment of mental illness and substance dependence in remote Indigenous communities: Results of a mixed methods study', *Australian Journal of Rural Health*, vol. 17, pp. 174-182.

Neutze, M 2000, 'Housing for Indigenous Australians', *Housing Studies*, vol. 15, no. 4, pp. 485-504.

North Australia Aboriginal Justice Agency 2016, *Response to the Housing Strategy Consultation Draft*, Darwin, NAAJA.

Northern Territory Department of Health 2017, *Northern Territory Market Basket Survey 2016*, Darwin, Northern Territory Department of Health.

Northern Territory Department of Health 2018, *Fishing in Darwin Creeks*, Darwin, Northern Territory Department of Health.

Northern Territory Department of Health 2019a, *Factsheet – Defining the roles of Aboriginal Health Workers & Aboriginal Health Practitioners*, Darwin, Northern Territory Government.

Northern Territory Department of Health 2019b, *Kidney and renal services*, Accessed 29 Nov 2019 https://nt.gov.au/wellbeing/hospitals-health-services/kidney-and-renal-services.

Northern Territory Department of Housing and Community Development 2015, *Temporary vacancy of your public housing home*, Accessed 24 April 2019 https://nt.gov.au/property/public-housing/tenants-your-rights-and-responsibilities/temporary-vacancy-of-your-public-housing-home.

Northern Territory Department of Housing and Community Development 2016, *Guide to Public Housing Tenancy Agreement*, Darwin, Northern Territory Government.

Northern Territory Department of Housing and Community Development 2017, *Rental Rebate Policy v2.02*, Darwin, Northern Territory Government.

Northern Territory Department of Housing and Community Development 2018a, *Annual Report 2017-18*, Darwin, Northern Territory Government.

Northern Territory Department of Housing and Community Development 2018b, *Public Housing Waiting List*, Accessed 23 September 2018 https://nt.gov.au/property/public-housing/apply-for-housing/apply-for-public-housing/waiting-list.

Northern Territory Department of Local Government Housing and Community Development 2020, *Priority Housing*, Darwin, Northern Territory Department of Local Government Housing and Community Development.

Northern Territory Department of Primary Industry and Resources 2017, *NT Fisheries*, Accessed 11 April 2019 https://dpir.nt.gov.au/fisheries.

Northern Territory Government 2016, *Northern Territory Health Aboriginal Cultural Security Framework*, Darwin, Northern Territory Government.

Northern Territory Government 2017a, *Budget Overview 2017-18*, Darwin, Northern Territory Government.

Northern Territory Government 2017b, *Northern Territory Renal Services Strategy 2017-2021*, Darwin, Northern Territory Department of Health.

Northern Territory Government 2018a, *Departmental and agency media releases*, Accessed 27 Feb 2019 http://mediareleases.nt.gov.au/.

Northern Territory Government 2018b, *Pathways out of Homelessness: Northern Territory Homelessness Strategy 2018-23*, Darwin, Department of Housing and Community Development.

Northern Territory Government 2019, *2019-20 Budget Papers: Northern Territory Economy*, Darwin, Northern Territory Government.

Northern Territory Library 2019, *Explore NT History: Resources Package*, Darwin, NTL.

NT Shelter 2016, 'Resetting the Homelessness and Housing Button for the Northern Territory?', *Parity*, vol. 29, no. 8, pp. 34-35.

Obialo, C, Hunt, W, Bashir, K & Zager, P 2012, 'Relationship of missed and shortened hemodialysis treatments to hospitalization and mortality: observations from a US dialysis network', *Clinical Kidney Journal*, vol. 5, no. 4, pp. 315-319.

Ortner, S 1984, 'Theory in Anthropology since the Sixties', *Comparative Studies in Society and History*, vol. 26, no. 1, pp. 126-166.

Owen, JR 2009, *A History of the Moral Economy: Markets, Custom and the Philosophy of Popular Entitlement*, Melbourne, Australian Scholarly Publishing.

Paech, C 2019, 'Conference opening', in *Share a Tale*, Alice Springs Convention Centre, 9-11 April, Alice Springs.

Palomera, J & Vetta, T 2016, 'Moral Economy: Rethinking a radical concept', *Anthropological Theory*, vol. 16, no. 4, pp. 413-432.

Passaro, J 1997, 'You can't take the subway to the field!': 'Village' epistemologies in the global village', in A Gupta & J Ferguson (eds), *Anthropological Locations: Boundaries and Grounds of a Field Science*, Berkeley, University of California Press, pp. 147-162.

Pera Tane, M & Harwood, M 2017, 'Decolonizing Research Methodologies in East Arnhem Land', *Learning Communities*, vol. 22, pp. 48-68.

Peterson, N 1993, 'Demand Sharing: Reciprocity and the Pressure for Generosity among Foragers', *American Anthropologist*, vol. 95, no. 4, pp. 860-874.

Peterson, N 1998, 'Welfare Colonialism and Citizenship: Politics, Economics and Agency', in N Peterson & W Sanders (eds), *Citizenship and Indigenous Australians: Changing Conceptions and Possibilities*, Cambridge, Cambridge University Press, pp. 101-117.

Peterson, N 2013, 'On the persistence of sharing: Personhood, asymmetrical reciprocity, and demand sharing in the Indigenous Australian domestic moral economy', *The Australian Journal of Anthropology*, vol. 24, pp. 166-176.

Peterson, N & Myers, F (eds) 2016, *Experiments in self-determination: histories of the outstation movement in Australia*, Canberra, ANU Press.

Peterson, N & Taylor, J 2003, 'The modernising of the Indigenous domestic moral economy', *The Asia Pacific Journal of Anthropology*, vol. 4, pp. 105-122.

Petryna, A 2002, *Life Exposed: biological citizens after Chernobyl*, Princeton, Princeton University Press.

Petryna, A 2012, 'Medicine', in D Fassin (ed.), *A Companion to Moral Anthropology*, West Sussex, Wiley Blackwell, pp. 376-394.

Pholeros, P, Rainow, S & Torzillo, S 1993, *Housing for Health: Towards A Healthy Living Environment for Aboriginal Australia*, Newport Beach, Healthabitat.

Pollak, M 2017, 'Care in the Context of a Chronic Epidemic: Caring for Diabetes in Chicago's Native Community', *Medical Anthropology Quarterly*, vol. 32, no. 2, pp. 196–213.

Povinelli, E 2002, *The Cunning of Recognition: Indigenous Alterities and the Making of Australian Multiculturalism*, Durham, Duke University Press.

Povinelli, E 2011, *Economies of Abandonment: Social Belonging and Endurance in Late Liberalism*, Durham and London, Duke University Press.

Power, ER & Bergan, TL 2018, 'Care and Resistance to Neoliberal Reform in Social Housing', *Housing, Theory and Society*, vol. 36, no. 4, pp. 426-447.

Power, ER & Mee, KJ 2019, 'Housing: an infrastructure of care', *Housing Studies*, vol. 35, no. 3, pp. 1-22.

Prince, R 2012, 'HIV and the Moral Economy of Survival in an East African City', *Medical Anthropology Quarterly*, vol. 26, no. 4, pp. 534-556.

Productivity Commission 2017, *Horizontal Fiscal Equalisation Draft Report*, Canberra, Australian Government.

Prout Quicke, S & Green, C 2017, 'Precarious residence: Indigenous housing and the right to the city', *Geoforum*, vol. 85, pp. 167-177.

Prout, S 2008, *The entangled relationship between Indigenous spatiality and government service delivery*, CAEPR Working Paper No. 41, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Puig de la Bellacasa, M 2017, *Matters of Care: Speculative Ethics for a More than Human World*, Minneapolis, Minnesota University Press.

Puszka, S 2009, *Regulating Responsibilities: Impacts of income management at Mäpuru*, Honours thesis, Charles Darwin University.

Puszka, S 2019, *Improving access to housing for Aboriginal and Torres Strait Islander renal patients with complex care needs*, Canberra, Deeble Institute Issues Brief 30.

Puszka, S, Greatorex, J & Williams, G 2013, 'Regulating Responsibilities: Income Management, Community Engagement and Bureaucratic Learning at Mäpuru, North East Arnhem Land', *Learning Communities*, vol. 13, pp. 59-73.

Rapport, N 2018, 'The action and inaction of care: Care and the personal preserve', *The Australian Journal of Anthropology*, vol. 29, no. 2, pp. 250-257.

Raynes, CM 2000, *'Very Hard, That Day': The moral sub-text of Aboriginal oral history from the western Victoria River Region, Northern Territory*, PhD thesis, Northern Territory University.

Read, P (ed.) 2000, *Settlement: A History of Australian Indigenous Housing*, Canberra, Aboriginal Studies Press.

Reid, J 1983, *Sorcerers and Healing Spirits: Continuity and Change in an Aboriginal Medical System*, Canberra, Australian National University Press.

Reubi, D 2018, 'Epidemiological accountability: philanthropists, global health and the audit of saving lives', *Economy and Society*, vol. 47, no. 1, pp. 83-110.

Rivalland, P 2006, *"It's more than machines and medicine - they should understand there's a Yanangu way": Summary Report*, Alice Springs, Cooperative Research Centre for Aboriginal Health.

Rix, EF, Barclay, L, Stirling, J, Tong, A & Wilson, S 2014, ''Beats the alternative but it messes up your life': Aboriginal people's experience of haemodialysis in rural Australia', *BMJ Open*, vol. 4, no. 9.

Rix, EF, Moran, C, Kapeen, R & Wilson, S 2016, 'Building cultural bridges and two-way understanding: working with Australian Aboriginal people within mainstream renal services', *Renal Society of Australasia Journal*, vol. 12, no. 1, pp. 12-17.

Roitman, J 2005, *Fiscal Disobedience: An Anthropology of Economic Regulation in Central Africa*, Princeton and Oxford, Princeton University Press.

Rona-Tas, A & Guseva, A 2018, 'Consumer Credit in Comparative Perspective', *Annual Review of Sociology*, vol. 44, pp. 55-75.

Rose, N 2007, *The Politics of Life Itself : Biomedicine, Power, and Subjectivity in the Twenty-First Century*, Princeton and Oxford, Princeton University Press.

Ross, H 2000, 'Lifescape and Lived Experience', in P Read (ed.), *Settlement: A History of Australian Indigenous Housing*, Canberra, Aboriginal Studies Press.

Rowse, T 1998, *White Flour, White Power: From rations to citizenship in Central Australia*, Melbourne, Cambridge University Press.

Rudd, K 2008, *Apology to Australia's Indigenous Peoples*, Accessed 19 April 2017 http://www.australia.gov.au/about-australia/our-country/our-people/apology-to-australias-indigenous-peoples.

Rummery, K & Fine, M 2012, 'Care: A Critical Review of Theory, Policy and Practices', *Social Policy and Administration*, vol. 46, no. 3, pp. 321–343.

Rutherford, D 2012, *Laughing at Leviathan: Sovereignty and audience in West Papua*, Chicago, University of Chicago Press.

Saethre, E 2013, *Illness is a Weapon: Indigenous Identity and Enduring Afflictions*, Nashville, Vanderbilt University Press.

Sahlins, M 1974, *Stone Age Economics*, London, Tavistock.

Samimian-Darash, L & Rabinow, P 2015, 'Introduction', in L Samimian-Darash & P Rabinow (eds), *Modes of Uncertainty: Anthropological Cases*, Chicago and London, The University of Chicago Press, pp. 1-12.

Sanders, W 2005, *Housing Tenure and Indigenous Australians in Remote and Settled Areas*, CAEPR Discussion Paper No. 275, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Sanders, W 2008, *Equality and Difference Arguments in Australian Indigenous Affairs: Examples from income support and housing*, CAEPR Working Paper No. 38, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Sanders, W 2014, *Experimental governance in Australian Indigenous affairs: From Coombs to Pearson via Rowse and the competing principles*, CAEPR Discussion Paper No. 291, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Sansom, B 1980, *The camp at Wallaby Cross: Aboriginal fringe dwellers in Darwin*, Canberra, Australian Institute Of Aboriginal Studies.

Sansom, B 1982, 'The Sick Who Do Not Speak', in D Parkin (ed.), *Semantic Anthropology*, London, Academic Press, pp. 183-195.

Sansom, B 1988, 'A grammar of exchange', in I Keen (ed.), *Being Black: Aboriginal Cultures in 'Settled' Australia*, Canberra, Aboriginal Studies Press, pp. 159-177.

Scarry, E 1985, *The Body in Pain: The Making and Unmaking of the World*, New York, Oxford, Oxford University Press.

Scheper-Hughes, N 1994, 'Embodied Knowledge: Thinking with the Body in Critical Medical Anthropology', in R Borofsky (ed.), *Assessing Cultural Anthropology*, New York, McGraw-Hill, pp. 229-242.

Scheper-Hughes, N 1995, 'The Primacy of the Ethical: Propositions for a Militant Anthropology', *Current Anthropology*, vol. 36, no. 3, pp. 409-440.

Scheper-Hughes, N 2002, 'Commodity Fetishism in Organs Trafficking', in N Scheper-Hughes & L Wacquant (eds), *Commodifying Bodies*, London, Thousand Oaks, New Delhi, Sage Publications, pp. 30-55.

Scheper-Hughes, N 2007, 'The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants', *American Journal of Transplantation*, vol. 7, pp. 507–511.

Schrecker, T 2014, 'Changing cartographies of health in a globalizing world', *Medicine Anthropology Theory*, vol. 1, no. 1, pp. 145–180.

Schwarz, C 2017, 'Eating Morality: Food and the Goodness of Care in Northern Aboriginal Australia', *The Asia Pacific Journal of Anthropology*, pp. 1-16.

Scott, J 1976, *The Moral Economy of the Peasant*, New Haven and London, Yale University Press.

Scott, J 1998, *Seeing Like A State: How Certain Schemes to Improve the Human Condition Have Failed*, New Haven and London, Yale University Press.

Seligman, R, Mendenhall, E, Valdovinos, M, Fernandez, A & Jacobs, E 2014, 'Self-care and Subjectivity among Mexican Diabetes Patients in the United States', *Medical Anthropology Quarterly*, vol. 29, no. 1, pp. 61-79.

Senior, K & Chenhall, R 2013, 'Health Beliefs and Behavior: The Practicalities of “Looking after Yourself” in an Australian Aboriginal Community', *Medical Anthropology Quarterly*, vol. 27, no. 2, pp. 155-174.

Sercombe, H 2008, 'Living in two camps: The strategies Goldfields Aboriginal people use to manage in the customary economy and the mainstream economy at the same time', *Australian Aboriginal Studies*, vol. 2, pp. 16-31.

Sevenhuijsen, S 1998, *Citizenship and the Ethics of Care: Feminist considerations on justice, morality and politics*, London and New York, Routledge.

Shen, TC, Wang, IK, Wei, CC, Lin, CL, Tsai, CT, Hsia, TC, Sung, FC & Kao, CH 2014, 'The Risk of Septicemia in End-Stage Renal Disease With and Without Renal Transplantation: A Propensity-Matched Cohort Study', *Medicine (Baltimore)*, vol. 94, no. 34.

Silverstein, P 2004, 'Of rooting and uprooting: Kabyle habitus, domesticity, and structural nostalgia', *Ethnography*, vol. 5, no. 4, pp. 553-578.

Singer, M & Baer, H 1995, *Critical Medical Anthropology*, New York, Baywood Publishing Company.

Smee, B & Walsh, CA 2016, *Crocs in the Cabinet*, Sydney, Hachette Australia.

Smith, SJ 2005, 'States, markets and an ethic of care', *Political Geography*, vol. 24, pp. 1-20.

Smith-Morris, C 2018, 'Care as Virtue, Care as Critical Frame: A Discussion of Four Recent Ethnographies', *Medical Anthropology*, vol. 37, no. 5, pp. 426-432.

Soldatic, K 2018, 'Neoliberalising disability income reform: What does this mean for Indigenous Australians living in regional areas?', in D Howard-Wagner, M Bargh & I Altamirano- Jiménez (eds), *The Neoliberal State, Recognition and Indigenous Rights: New paternalism to new imaginings*, Canberra, ANU Press.

Soldatic, K & Fitts, M 2019, *'At what cost?' Indigenous Australians' experiences of applying for disability income support (Disability Support Pension)*, Sydney, Western Sydney University.

Soss, J, Fording, R & Schram, SF 2011, *Disciplining the Poor: Neoliberal paternalism and the persistent power of race*, Chicago and London, University of Chicago Press.

Stevenson, L 2014, *Life Beside Itself: Imagining Care in the Canadian Arctic*, Oakland, University of California Press.

Stewart, P & Strathern, A 2001, 'Origins versus Creative Powers: The Interplay of Movement and Fixity', in A Rumsey & J Weiner (eds), *Emplaced Myth: Space, Narrative, and Knowledge in Aboriginal Australia and Papua New Guinea*, Honolulu, University of Hawai'i Press, pp. 79-98.

Strathern, M 1988, *The gender of the gift: problems with women and problems with society in Melanesia*, Berkeley, University of California Press.

Street, A 2014, *Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinean Hospital*, Durham and London, Duke University Press.

Stumpers, S & Thomson, N 2013, *Review of kidney disease and urologic disorders among Indigenous people*, Australian Indigenous HealthInfoNet Reviews No. 11, Australian Indigenous HealthInfoNet, Perth.

Sutton, P 2009, *The Politics of Suffering: Indigenous Australia and the end of the liberal consensus*, Melbourne, Melbourne University Press.

Taee, J 2017, *The Patient Multiple: An Ethnography of Healthcare and Decision-Making in Bhutan*, New York, Berghahn Books.

Tamisari, F 2014, 'Feeling, Motion, and Attention in the Display of Emotions in Yolngu Law, Song, and Dance Performance', *Journal for the Anthropological Study of Human Movement*, vol. 21, no. 2.

Tate, W 2015, 'Introduction: Anthropology of Policy', in *Drugs, Thugs and Diplomats: US policymaking in Colombia*, pp. 1-25.

Tatz, C 2001, 'From Welfare to Treaty: Reviewing fifty years of Aboriginal policy and practice', paper presented to *The Power of Knowledge, the Resonance of Tradition: AIATSIS Indigenous Studies Conference, September*, Canberra.

Taussig, M 1980, *The Devil and Commodity Fetishism in South America*, Chapel Hill, University of North Carolina Press.

Taylor, J 1989, 'Public policy and aboriginal population mobility: insights from the Katherine region, Northern Territory', *Australian Geographer*, vol. 20, no. 1, pp. 47-53.

Taylor, J 2007, 'Demography is Destiny, Except in the Northern Territory', in J Altman & M Hinkson (eds), *Coercive Reconciliation: Stabilise, Normalise, Exit Aboriginal Australia*, North Carlton, Arena Publications, pp. 173-183.

Taylor, J 2008, 'On Recognition, Caring, and Dementia', *Medical Anthropology Quarterly*, vol. 22, no. 4, pp. 313-335.

Tentori, F, Hunt, W, Rohrscheib, M, Zhu, M, Stidley, C, Servilla, K, Miskulin, D, Meyer, K, Bedrick, E, Johnson, K & Zager, P 2007, 'Which Targets in Clinical Practice Guidelines Are Associated with Improved Survival in a Large Dialysis Organization?', *Journal of the American Society of Nephrology*, vol. 18, no. 8, pp. 2377-2384.

Thelen, T 2015, 'Care as social organization: Creating, maintaining and dissolving significant relations', *Anthropological Theory*, vol. 15, no. 4, pp. 497-515.

Thomas, D & Stevens, M 2014, 'Aboriginal and Torres Strait Islander smoke-free homes', *Australian and New Zealand Journal of Public Health*, vol. 38, no. 2, pp. 147-153.

Thomas, M 2004, 'Antecedents of renal disease in Aborigines', *Nephrology*, vol. 9, pp. s113-s116.

Thomas, R, Kanso, A & Sedor, J 2008, 'Chronic Kidney Disease and Its Complications', *Primary Care*, vol. 35, no. 2.

Thompson, EP 1991, 'The Moral Economy of the English Crowd in the 18th Century', in *Customs in Common*, London, Penguin Books, pp. 185-258.

Thomson, D 1949, *Economic Structure and the Ceremonial Exchange Cycle in Arnhem Land*, Melbourne, Macmillan and Co. Limited.

Thomson, D 1975, 'The Concept of 'Marr' in Arnhem Land', *Mankind*, vol. 10, no. 1, pp. 1-10.

Thomson, D 1983, *Donald Thomson in Arnhem Land*, Melbourne, Currey O'Neil Ross.

Thorpe, N 2017, *Governments must step up to the plate on life-saving dialysis treatment, Indigenous groups*, NITV News, 6 August. Distributed by NITV.

Ticktin, M 2011, *Casualties of Care: Immigration and the Politics of Humanitarianism in France*, Berkeley, University of California Press.

Trnka, S & Trundle, S 2014, 'Competing Responsibilities: Moving Beyond Neoliberal Responsibilisation', *Anthropological Forum*, vol. 24, no. 2, pp. 136-153.

Tronto, J 1993, *Moral Boundaries: A Political Argument for an Ethic of Care*, New York and London, Routledge.

Trouillot, M 2001, 'The Anthropology of the State in the Age of Globalization: Close Encounters of the Deceptive Kind', *Current Anthropology*, vol. 42, no. 1, pp. 125-138.

Trudgen, R 2000, *Why warriors lie down and die: Towards an understanding of why the Aboriginal people of Arnhem Land face the greatest crisis in health and education since European contact*, Darwin, Aboriginal Resource and Development Services Inc.

Tsutsui, H, Koike, T, Yamazaki, C, Ito, A, Kato, F, Sato, H, Tawada, H & Oshida, Y 2009, 'Identification of Hemodialysis Patients' Common Problems Using the International Classification of Functioning, Disability and Health', *Therapeutic Apheresis and Dialysis*, vol. 13, no. 3, pp. 186-192.

Tuhiwai Smith, L 1999, *Decolonizing Methodologies: Research and Indigenous Peoples*, London, Zed Books.

University of New South Wales & Australian Council of Social Service 2018, *Povery in Australia 2018*, Strawberry Hills, Australian Council of Social Service and University of New South Wales.

van Ommen, C, Cromby, J & Yen, J 2016, 'The contemporary making and unmaking of Elaine Scarry's The Body in Pain', *Subjectivity*, vol. 9, no. 4, pp. 333-342.

Varul, MZ 2010, 'Talcott Parsons, the Sick Role and Chronic Illness', *Body and Society*, vol. 16, no. 2, pp. 72-94.

Villarba, A & Warr, K 2004, 'Home haemodialysis in remote Australia', *Nephrology*, vol. 9, pp. s134-s137.

von Sturmer, D 1980, *Rights in nurturing: The social relations of child-bearing and rearing amongst the Kugu-Nganychara, western Cape York Peninsula, Australia*, MA thesis, Australian National University.

Warner, WL 1937, *A Black Civilisation: A Social Study of an Australian Tribe*, Gloucester, Peter Smith.

Watson, V 2004, 'Axing ATSIC: Australian Liberalism and the "Government of Unfreedom"', *Politics and Society*, vol. 23, no. 4, pp. 57-81.

Weicht, B 2011, 'Embracing dependency: rethinking (in)dependence in the discourse of care', *The Sociological Review*, vol. 58, pp. 205-224.

Weiner, A 1980, 'Reproduction: A Replacement for Reciprocity', *American Ethnologist*, vol. 7, no. 1, pp. 71-85.

Wells, E 1982, *Reward and Punishment in Arnhem Land 1962-1963*, Canberra, Australian Institute of Aboriginal Studies.

Wells, S 1995, *Town Camp or Homeland? A History of the Kulaluk Aboriginal Community*, Darwin, Australian Heritage Commission.

Wells, S 2000, 'Labour, Control and Protection: The Kahlin Aboriginal Compound, Darwin, 1911-38', in P Read (ed.), *Settlement: A History of Australian Indigenous Housing*, Canberra, Aboriginal Studies Press, pp. 64-74.

Westbury, N 1999, *Feast, famine and fraud: Considerations in the delivery of banking and financial services to remote communities*, CAEPR Discussion Paper No. 187, Centre for Aboriginal Economic Policy Research, Australian National Universtiy, Canberra.

Whiteford, LM & Tobin, GA 2004, 'Saving Lives, Destroying Livelihoods: Emergency Evacuation and Resettlement Policies in Ecuador', in A Castro & M Singer (eds), *Unhealthy Health Policy: A Critical Anthropological Examination*, Maryland, AltaMira Press, pp. 189-202.

Wilkinson, I 2006, 'Health, risk and 'social suffering'', *Health, Risk and Society*, vol. 8, no. 1, pp. 1-8.

Willems, D 2010, 'Varieties of goodness in high-tech home care', in A Mol, I Moser & J Pols (eds), *Care in Practice: On Tinkering in Clinics, Homes and Farms*, Bielefeld, Transcript, pp. 257-276.

Williams, A 2002, 'Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space', *Social science and medicine*, vol. 55, pp. 141–154.

Williams, N 1986, *The Yolngu and their Land: A System of Land Tenure and the Fight for its Recognition*, Canberra, Australian Institute of Aboriginal Studies.

Williams, P 2017, *Dr G Yunupingu*, Melbourne. Distributed by Madman Entertainment.

Willis, J 1995, 'Fatal attraction: do high-technology treatments for end-stage renal disease benefit Aboriginal patients in central Australia?', *Australian Journal of Public Health*, vol. 19, no. 6, pp. 603-609.

Wilson, R, Krefting, L, Sutcliffe, P & Van Bussel, L 1994, 'Native Canadians relocating for renal dialysis: Psychosocial and cultural issues', *Canadian Family Physician*, vol. 40, pp. 1934-1941.

Wong, J, Vilar, E & Farrington, K 2014, 'Endotoxemia in End-Stage Kidney Disease', *Seminars in Dialysis*, vol. 28, no. 1, pp. 59-67.

Wong, M, Ghebleh, P & Phillips, S 2017, 'Tips for Dialysis Patients With Fluid Restrictions', *Journal of Renal Nutrition*, vol. 27, no. 5, pp. e35-e38.

Yolŋu Nations Aboriginal Corporation 2018, *Yolŋu Nations Assembly*, Accessed 31 July 2019 http://www.yolngunations.org/.

Yothu Yindi 2012, *Healing Stone: The best of Yothu Yindi*, Liberation Music, Melbourne.

Yothu Yindi Foundation 2017a, 'Garma Festival Live Forum', in *Garma Festival*, August, Gulkula.

Yothu Yindi Foundation 2017b, *Submission to the Productivity Commission Inquiry into Horizontal Fiscal Equalisation*, Canberra, Productivity Commission.

You, J, Lawton, P, Zhao, Y, Poppe, S, Cameron, N & Guthridge, S 2015, *Renal Replacement Therapy Demand Study, Northern Territory 2001 to 2022*, Darwin, Northern Territory Department of Health.

You, J, Zhao, Y, Lawton, P, Guthridge, S, Macdonald, S & Cass, A 2017, 'Projecting demands for renal replacement therapy in the Northern Territory: a stochastic Markov mode', *Australian Health Review*, vol. 42, no. 4, pp. 380-386.

Young, E & Doohan, K 1989, *Mobility for survival: A process analysis of Aboriginal population movement in central Australia*, North Australia Research Unit Monograph, Australian National University, Darwin.

Yunupingu, G 2008, 'Tradition, Truth and Tomorrow', *The Monthly*, December 2008 - January 2009, Schwartz Media, Melbourne.

Yunupingu, G 2009, 'Locked out of the economic future', *The Australian Inquirer*, 4 July, p. 23.

Zachariah, D, Kalra, PR & Roberts, PR 2015, 'Sudden cardiac death in end stage renal disease: unlocking the mystery', *Journal of Nephrology*, vol. 28, no. 2, pp. 133-141.

Zelizer, VA 2009, *The Purchase of Intimacy*, Princeton and Oxford, Princeton University Press.

Zelizer, VA 2011, *Economic Lives*, Princeton and Oxford, Princeton University Press.

Zhao, Y, Poppe, S, Lawton, P, Hutchings, J, You, J, Annesley, K, Cameron, N & Guthridge, S 2014, *Satellite Dialysis Costs in the Top End, 2011-2013*, Darwin, Northern Territory Department of Health.

Zinn, JO 2012, 'More Irresponsibility for Everyone?!', in G Hage & R Eckersley (eds), *Responsibility*, Melbourne, Melbourne University Press, pp. 38-55.

Appendix 1: Informed consent materials

Living in Darwin for Dialysis Project

For people with kidney disease
Participant Information Sheet (This is for you to keep)

What is the research about?

This study is about Yolŋu people's experiences of kidney disease and moving to Darwin for dialysis. We would like to find out about what happens when Yolŋu move to Darwin and how people get food, housing or accommodation and Centrelink payments. We would like to understand how Yolŋu in Darwin stay in contact with their families and how they make connections with family members and other people in Darwin. We will also be speaking with nurses, doctors and other health workers about dialysis and patient support services. We will talk to government workers and read government reports to find out how the government thinks about kidney disease and providing dialysis services.

Who should you contact to find out more?

If you have any questions about the study or if you want to stop being involved contact:

Stefanie Puszka (PhD student – Darwin):
Stefanie.Puszka@menzies.edu.au or Ph. 0401 301 204

Dr Katherine Curchin (supervisor – Canberra):
Katherine.Curchin@anu.edu.au or Ph. (02) 6125 4746

Who can be involved?

We would like to work together with Yolŋu with kidney disease and their families living in Darwin for dialysis.

What will you be asked to do?

- We would like to work together with you and your family in Darwin for about one year so that we can get to know you and understand your story.
- We would like to talk to you and your family about kidney disease and living in Darwin.
- If it's ok with you and you agree, we would like to record some of our talks on my phone.
- If it's ok with you and you agree, we might go shopping together and we might visit you where you are living to help us understand everyday life for Yolŋu in Darwin.
- If it's ok with you and you agree, we might go with you to dialysis or Centrelink or other places to help us understand how easy it is to access these services.
- We would like to see you about once a week. We might spend one hour or up to half a day together.

Menzies School of Health Research
Postal: PO Box 41096, Casuarina NT 0811 Australia
Location: John Mathews Building (Bldg 58)
Royal Darwin Hospital Campus, Rocklands Drv, Casuarina NT 0810
Ph: (08) 8946 8600 Fax: (08) 8946 8464
Website: menzies.edu.au

Who is conducting this research?

This research is being done by Stef Puszka as part of her PhD. Yinin Dhurrkay and (name removed) (co-researchers) are working with Stef. This project involves the Centre for Aboriginal Economic Policy Research at the Australian National University and Menzies School of Health Research at Charles Darwin University working together. The people supervising the project are: Dr Katherine Curchin, Dr Caroline Schuster, Prof Francesca Merlan (ANU); Prof Alan Cass, Dr Paul Lawton (Menzies). The money for this research is provided by the National Health and Medical Research Council.

What are the risks and benefits?

Talking about dialysis and living in Darwin might make you feel upset or stressed. Talking about your life might also help you to feel better. If you are feeling stressed or would like some counseling after talking to the researchers or for other reasons, we can help you to get counseling services. If you would like counseling, we will give you information about free counseling services and we might be able to help with transport.

If you decide to be involved in the research, we can help you get support services and fill in forms (eg: for Centrelink, support services etc). We might be able to help with some trips around Darwin sometimes, during the research.

Being involved in this study will help us to understand the experiences of Yolŋu people on dialysis in Darwin. We would like to find out how well services like Centrelink, patient travel, housing, hostels etc are supporting patients. We would like to understand how families are involved in supporting patients and how people keep their connections to their country. We will write a report about how support services for people with kidney disease can be improved to take to the government. This might help Yolŋu leaders talk to government about getting better services. The research might help you and other people who have kidney disease in the future.

How many people are involved?

About 4 - 8 people with kidney disease and their families will be involved.

Do I have to be in the study?

Participation is voluntary (it is up to you).
You can refuse (say no to) any part of this study. Whether you say yes or no to the research, you will receive the same care. You can withdraw (stop) at any time until June 2019.

What happens to your information?

All the information that you provide will stay confidential. It will not be shared with anyone who is not involved in the research. We will not publish your name, community or clan group. We will only share photos with your consent. We will share the main findings of the study with you before we publish them. The findings of the study will be published in a book. Findings might also be published in articles or reports or presented at conferences. All your information will be kept in locked filing cabinets (cupboards) and on computers with passwords at Menzies School of Health Research. Information will be kept at Menzies School of Health research for five years after publication. Afterwards, your information will be moved to Menzies secure archives.

It's ok to change your mind about being involved in the study at any time. Please let us know if you would like to stop and pull out. If you decide to pull out from the study before June 2019, your information will be destroyed.

Three ethics committees have approved this research: the Human Research Ethics Committee of the NT Department of Health and Menzies School of Health Research (ref 2017-2921), the Human Research Ethics Committee of Charles Darwin University (ref H17133) and the Human Research Ethics Committee of the Australian National University (ref 2017/760).

If you wish to make a complaint about this study contact:

The Human Research Ethics committee for the Department of Health and Menzies School of Health Research Ph: (08) 8946 8687 or (08) 8946 8692 or ethics@menzies.edu.au

In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. The ANU Privacy Policy is available at https://policies.anu.edu.au/ppl/document/ANUP_010007 and it contains information about how a person can access or seek correction to their personal information; or complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

If you are worried about the information you provide in this study staying private, you can find out about your rights and make a complaint using this link.

menzies school of health research
Australian National University

Menzies School of Health Research
Postal: PO Box 41096, Casuarina NT 0811 Australia
Location: John Mathews Building (Bldg 58)
Royal Darwin Hospital Campus, Rocklands Drv, Casuarina NT 0810
Ph: (08) 8946 8600 Fax: (08) 8946 8464
Website: menzies.edu.au

Nhina ga dhiyal Darwin-ŋur dialysis-puy: research project

Source: abc.net.au

Nhina ga Darwin-ŋur dhukarr ga malŋ'maram ga dhäwu dialysis-gu.

Marŋgithirr limurr dhu bulu dialysis-gu dhäwuw.

Manymak limurr dhu marŋgithirr nhä dialysis-gu dhukarr.

What this research is about

Nhäpuy dhuwal research

Dharrway Yolŋuy ga märram rerri yäku kidney disease. Wiripuny walal märraman ga mirritjinha.

Wiripuny walal ŋuli marrtji räli Darwin-lila ŋurruyirryurrnharawnha mirritjinkun märranharawnha.

Wiripuny napurr ŋuli yoram dhiyak nhinanaraw mirritjingu märramnharaw ga wiripuny napurr dhu yäka'yuna nhinanharaw dhiyak Darwin-gu.

Gumurr-ḏäl ŋayi wirirpuny dhuwal wäŋa Darwin nhinanaraw balanya nhakun rrupiyakurr, ŋathakurr ga waŋakurr.

Dhuwandja dhäwu nhaltjan ga Yolŋu kidney rerrimirr nhina dhiyal Darwin-ŋur

Dhukarr napurr ga maḷŋ'maram nhaltjan nhe ŋuli Yolŋuy rerrimirriy maḷŋ'maram rrupiya, wäŋa ga ŋatha dhiyal Darwin-ŋur.

Ŋapurr ga birrka'yun ga maḷŋ'maram rerrimirriwal Yolŋuwal walalaŋgal nhaltjan walal ŋuli ga nhäma guŋga'yunawuy gabmanguŋ ga yol mala nhanŋu waŋa balanya nhakun community service-guŋ mala. Ŋunha nhakun Centrelink, hostels, aged care, Purple House, renal unit, Danila Dilba, Royal Darwin Hospital ga bulu dharrwa mirithirr.

Wanhawitjan dhukarrkurr napurr dhu maḷŋ'maram ŋuli balaŋ nhe ga waŋa nhokiyingal nhe gurruṯumirriwal

Who is doing this research

Stef Puszka
PhD student

(Image removed)

Yinin Dhurrkay
Co-researcher

(Image removed)

(Name removed)
Co-researcher

Menzies School of Health Research, Charles Darwin University
Centre for Aboriginal Economic Policy Research, Australian National University

Yol dhuwal research djämamirr mala

Dhiyaŋuny bala ŋarra ga marŋgithirr ŋarra dhu researcher-thirr.

Marŋgithirr ŋarra ga dhiyal Darwin Menzies-ŋur ga wiripupuny ŋunha bala Australian National University-ŋur Canberra.

Ŋarra ga nhina dhiyal Darwin-ŋur.

Djama ŋarra ŋuli ga research Yiningal ga (name removed).

Maṉḏa ga djälthirr ŋarraku, ŋarra dhu djäma manymakkurr ga dharaŋanakurr dhukarrkurr.

Maṉḏa ga marŋgi-gurrpupan ŋarrany nhaltjan dhu marŋgithirr bulu Yolŋu romgu ga nhä rom ŋuli ga ŋorra limurruŋgal djälkiriŋur

Mala djarr'yun napurr ga dhiyak djämaw research-gu Balanda ga Yolŋukurr dhärukkurr.

Dhiyak research-gu djämaw ga guŋga'yun napurruny beŋur NHMRC-ŋur.

Who is advising on this research

Prof Alan Cass
Menzies School of Health Research
CDU

Dr Paul Lawton
Menzies School of Health Research
CDU

Prof Francesca Merlan
School of Archaeology & Anthropology
ANU

Dr Katherine Curchin
Centre for Aboriginal Economic Policy Research
ANU

Dr Caroline Schuster
School of Archaeology & Anthropology
ANU

Yol guŋga'yunamirr mala dhiyak research-gu djämaw

Nhaltjan ŋarra ga djäma dhuwalatjan research-kurr djämakurr.

Ga marŋgi-gurrupan nhaltjan ga wanhawitjan dhukarrkurr ŋarra dhu djäma.

Märrmany maṉḏa ŋuli ga djäma dhuwal Menziens-ŋur Darwin. Yäkuny maṉḏa Paul Lawton ga Alan Cass.

Ga ḻurrkundja ŋunha Canberra-ŋur ga yäku walal Katherine Curchin ga Caroline Schuster ga Francesca Merlan.

What we will do

Nhaltjan limurr dhu

Research-dja dhuwal mulkuru dhäruk Balandaw. Nhaltjan dhu maḷŋ'maram dhäwu. Wiripuny nhanŋu mayali research-gu djämaw dhukarr ga maḷŋ'maram ga mayali dharaŋanaraw.

Dharrwa ga dhukarr ŋorra research-gu djämaw balanya nhakun dhäwu ga märram Yolŋuwal rerrimirriwal.

Dhiyak research-gu dhukarr ga ŋorra napurr dhu nhina gurruṯumirriwal ga nhina ga waŋanhamirr dhiyakuwuy research-puy.

Nhokiyingal or nhumalaŋgiyingal guyaŋanhawuylil ŋuli nhuma dhu malthun djämamirriw mala napurruŋ dolil, ŋathaw rrambaŋiw ḻukanharaw.

Ŋunhi nhuma ga djälthirr marrtjinyaraw balanya nhakun Centerlink-lil, renal-lil or wiripuŋulil wäŋalil marŋgi-gurrupul napurruny djämamirriny mala.

Wiripuny napurr dhu nhumalany guwatjman hostellil or watjpilil or ŋula wanha nhe ga nhina.

Napurr ga djälthirr napurr dhu nhina ga waŋa nhumalaŋgal gurruṯumirriwal ga maḷŋ'maram dhäwu.

Ŋayaŋulil napurr dhu ganarrtham nhokal nhaltjan nhe dhu guyaŋa rirrakaywu ḏapmarantharaw.

Ga nhaltjan nhe dhu guyaŋa wuŋiḻiw djaw'yunaraw. Wuŋiḻi ga dhäwu nhuŋu dhu gärri djorralil.

Märr bukmak Yolŋu dhu marŋgithirr.
Yäku ga wuŋiḻi nhuŋu dhu bäyŋu gärri dhipal djorralil.
Nheny dhu ga dhärra yan dhiyal research-ŋur djämaŋur bäydhi ŋunhi nhe dhu yäka'yun nhokalaŋaw wuŋiḻiw gärrinyaraw.
Ŋuli nhe yäka djäl ŋayi dhu Yolŋu mala marŋgithirr ŋunhi nhe ga dhärra dhiyal research djämaŋur, nheny dhu yäka'yun wuŋiḻi ḏapmaranharaw.

How long I will be involved

Nhämunha weyin

Napurr dhu djäma waŋgany dhuŋgarra nhumalaŋgal renal-mirriwal Yolŋuwal mala ga nhokalaŋawal gurruṯumirriwal märr napurr dhu märram nhuŋu dhäwu ga bulu dharaŋanawuy.

Napurr research djämamirr mala dhu boŋguŋ marrtji ga nhäŋu nhunany biyak bili yurr napurr dhu ganarrtham nhäthaŋuw nhe dhu djälthi napurruŋ roŋiyinyaraw buluŋuw

Mäŋgikuŋ napurruny walu nhänharaw nhuŋu ga nhäkurr nhe dhu djälthi marrtjinyaraw limurr rrambaŋi.

It's up to you

manymak yurr yaka

Nhe dhu yoram wo yaka'yun dhiyak djämaw

Ŋuli nhe ga dhärra dhiyal research-ŋur ganydjarr nhuŋu ga ŋorra nhe dhu yoram wo yaka'yun dhiyak djämaw.

Wiripuny nhe dhu yoram wo yaka'yun dhiyak malaŋuw djämaw wo ŋunhi ga ŋorran bilin.

Ḻiya-ŋamaŋamayunmirr nhä nhe dhu dhäwu napurruŋ gurrupan.

Bawalamirriy waluy nhe dhu gulyun ga dhawaṯmaranhamirr dhipuŋur research djämaŋur.

Guyaŋanhawuy nhe dhu ḻakaram ga marŋgikum napurruny djämamirr mala ŋuli nhe dhu yaka'yun dhärranharaw dhiyak djämaw.

Yow marŋgi-gurrupul napurruŋ djämamirriny mala.

Ŋuli balaŋ nhe dhu djälthi gulyunaraw dhiyak djämaw research-gu märr barrku märŋgikum napurruŋ djämamirriny mala märr napurr dhu nhuŋu dhäwu dhawaṯmaraŋ bala bowayakumun

Ga ŋunhi bili nhuŋu dhärraywuynydja dhukarr bäydhi nhe dhu yaka'yurr dhiyak research-gu djämaw. Mirritjindja nhe dhu boŋguŋ gi märraŋ yan bäyŋun dhu djämbi.

Dhukarr ga ŋorra nhuŋu ŋula nhaku dhäwu malaŋu nhe dhu ŋaŋ'thun napurruny djämamirriny mala.

The risks and benefits

Source: Ofxam Australia

Source: mhhum.com

centrelink

Wanha nhuma ga malŋ'maram gomurr-d̲al
Wanha nhumalaŋ ga ŋorra guŋga'yunawuy

Ga dhiyal research-ŋur ga ŋorra dharrwa mirrithir gämurru mala balanya nhakun nhaltjan nhe ga nhäma dhuwal rerri yäku kidney disease ga nhina dhiyal Darwin-ŋur. Wiripuny mak nhe ga warwuyun nhokalaŋaw gurruṯumiriw mala bili walal ga barrku nhina bala nhunany ŋuli warwuyunha ŋayatham

Ga mak bäy nhunany dhu guŋga'yun ŋuli nhe dhu ŋayaŋumirriyurr l̲akaranharaw napurruŋgal djämamirriwal mala nhä nhuŋu dhäwu.

Ŋuli nhe ga ŋayaŋu warwumirriyirr mäŋgikuŋ napurruny djämamirriny mala märr napurr dhu dhukarr malŋ'maram guŋga'yunaraw nhuŋu balanya nhakun counselling djämamirriny mala.

Ŋuli nhe djäl nhe dhu ga dhärra dhiyal research-ŋur limurr dhu goŋ-manapanmirr ga guŋgayunmirr.

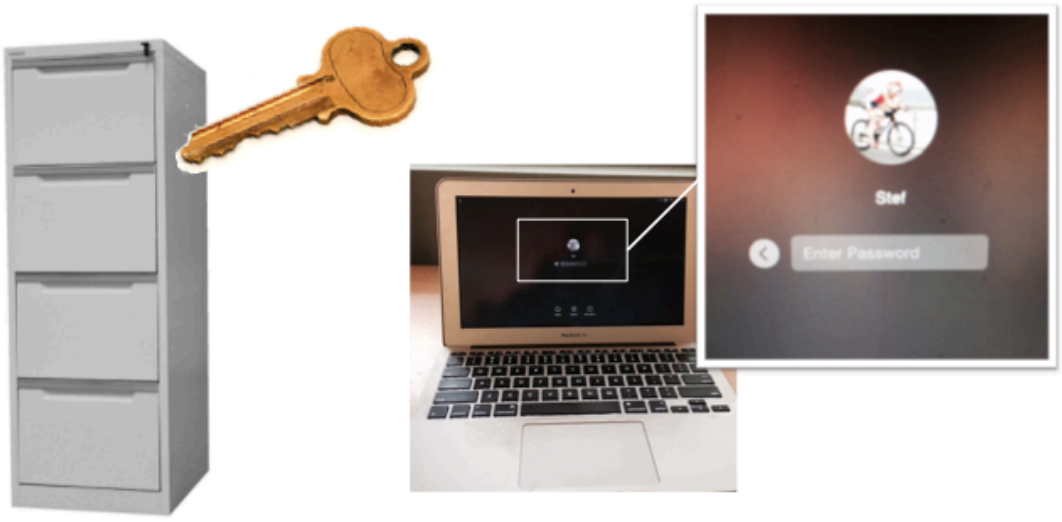
Ŋunhi nhe ga warwuyun ŋula nhaku napurru dhu nhunany guŋa'yun.

Dhiyaŋ research-dhu ga guŋga'yun renal patients-nha mala l̲akaranharaw dhäwuw marr dhu gabman-dhu dharaŋan

Napurr nhuna dhu guŋga'yun gäma nhunany Centrelink-lil wo ŋula nhakurr balanya nhakun, hospital, banks, Territory housing-lil.

Dhiyaŋ research-dhu ga guŋga'yun ga dhukarr l̲akaram yalalaŋumirriy yuṯaw Yolŋuw.

What will happen to my information



Nhäkurr nhuŋu dhäwumirr djorra, ḏapmaranhawuy rirrakay mala dhu marrtji

Dhäwumirrinydja djorra nhuŋu dhu boŋguŋ napurr rulwaŋdhurr wopitjlila

Ŋunhi dhäwu nhä nhe dhu gurrupul ga ḻakaraŋ napurruŋgal bäyŋun napurr dhu barrkuwatjkuŋ.

Bäyŋun dhu napurr mel-gurrupul wiripuŋuwal Yolŋuwal mala

Dhawaṯthurrunydja nhuŋu dhu boŋguŋ dhäwu ga yäkan wo bäyŋun yäkuny nhuŋu

Bäyŋu napurr dhu gurrupul nhunany yäku bukmakkal nhänharaw.

Bukmak dhu mukurr bukuḻuŋthurr bala napurr dhu nhäŋun nhuŋu dhäwuny

Ga nhä malaynha ŋunhi dhäwu limurr ga rrambaŋi djäma ŋunhiyiny dhu boŋguŋ marrtji dhäwumirrilil djorralil märr walal dhu wiripuŋuy Yolŋuy ga Balanday nhäŋu balanyamirriy waluy bäy limurr dhu bukuluŋthurr conference-gu.

Ga ŋunhiyi dhäwu nhokuŋ napurr dhu rulwaŋdhurr computer-lil ga gabitlil ŋunhi ga dhärra Menzies-ŋur.

Ga ŋuli balaŋ nhe dhu birrkayurr dhawaṯthunharaw dhipuŋur research djämaŋur Menzies-gal napurr nhuŋu dhu djorrany bowayakuŋun

What will happen to my information if I am no longer here

Nhäkurr ŋarraku dhu boŋguŋ marrtji ŋunhiyi dhäwu djämapuy yalalaŋumirriyinydja ŋuli balaŋ ŋarra dhu marrtjin

Dhuwal napurr marrtjin nhokal dhäwuw maḷŋ'maranharaw, nhaltjan nhe ga guyaŋa.

Dhiyakupuy djämawuy, nhalayak napurr dhu. bowayakum, wo gurrupul gurruṯmirriwal walalaŋgal.

Ŋuli nhe djäl nhe dhu ga dhärra dhiyal research djämaŋur, napurr dhu boŋguŋ märŋgi-gurrupul nhunany nhaliyak nhuŋu dhu dhäwu yalalaŋumiriw bäy nhe dhu marrtji ganarrthul napurruny.

Dhuwandja nhuŋu dhäwu, ŋunhi napurr dhu gurrupan nhokal. Nhaltjan limurr dhu?

Nhokiyingal guyanhawuylil ŋuli balaŋ napurr dhu bowayakuŋ nhuŋu dhäwu wo goŋ-gurrupul gurruṯumirriwal mala nhokal. Dhuwandja yalalaŋumiriw ŋunhi nhe dhu marrtjin, ganarrthula napurruny.

Ga ŋuli ŋayi dhu marrtjin ganarrtham limurruny, ŋunhi ŋayi ga dhärra dhiyal research study-ŋur, ga yäku nhanŋu bili gärri, napurr djämamirr mala dhu marrtji ga nhini ŋurukaliyi Yolŋuwal gurruṯumirriwal mala märr walal dhu ḻakaraŋ nhä manymak dhukarr.

Where I can find more information


Living in Darwin for Dialysis Project

For people with kidney disease
Participant information Sheet (This is for you to keep)

What is the research about?

Who should you contact to find out more?

What will you be asked to do?


Who is conducting this research?

What are the risks and benefits?

How many people are involved?

Do I have to be in the study?

What happens to your information?

If you wish to make a complaint about this study contact:

Ethical issues

Bulu dhäwu ga ŋorra

Ḻurrkunŋur rumbalŋur mala yäku walal ethics committees-ŋur bili yoram dhiyak research-gu dhipal Charles Darwin University-lil, Menzies School of Health Research-lil ga Australian National University-ŋur.

Bulu ga dhäwu ŋorra dhiyalaŋumi dhäwumirriŋur djorraŋur.

Ga ŋuli nhe bulu djäl dhäwuw ringimap ŋarraku dhipal number-lil.

Ŋuli nhokal dhu nhä ŋula miḏikirr dhuwalaŋuwuy djämapuy nhe dhu ringimap dhipal number-lil.

Ŋula nhä mala nhe ga guyaŋa nhe dhu ŋaŋ'thun napurruny bawalamirr.

Nhina ga dhiyal Darwin-ŋur dialysis-puy: research project

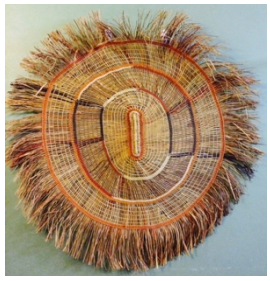
Dhuwal djorra Yolŋuw rerrimirriw kidney disease-mirriw ga walalaŋgal gurruŋumiriw

Dhuwal djorra yorranhamirr wo yaka'yunamirr

Nhatljan nhe dhu yoram wo yaka'yun?

Manymak nhe dhu djäma waŋgany dhuŋgarra napurruŋgal?

Notes:_____



Yes ☐ No ☐

Manymak ŋunhiyin napurr dhu nhunany nhäŋu waŋga-waŋganymirr waluy?

Notes: _____

Yes ☐ No ☐

Wanha ŋula nhe djäl napurr nhunany dhu gunga'yun nhäthaw märranharaw ga Centrelinklil ga watjpilil marrtjinyaraw?

Notes:

Yes ☐ No ☐

Nhä nhokalnydja manymak nhe dhu dhäwu gurrupan napurruŋgal nhuŋuwuy nhe ?

Notes: _____

Yes ☐ No ☐

Yes ☐ No ☐

Manymak nhokal napurr dhu nhunany rirrakay ga dhäwu nhuŋu dhipal rirrakay ḏapmaranhawuylil märram?

Notes: _____

Nhä nhokaldja manymak napurr dhu wuŋili djaw'yun nhunany?

Yes ☐ No ☐

Notes: _____

Dhukarr limurr dhu malŋ'maram yalalaŋumiriw ŋuli nhe dhu marrtjin ganarrthula napurruny
Ŋäthilmirriyaŋ nhuŋuwuy guyaŋanhawuy dhiyak ŋunhi dhäwuw ga wuŋiliw malaŋuw nhokalaŋuw. Nhaltjan nhe ga guyaŋa?

_____
_____
_____

Ŋula nhe ga dharaŋan ga märraŋal nhäpuy dhuwal dhäwu nhe ga ŋäma?

Ga dhuwal dhäwu malaynha nhe ŋunhi nhe l̪akaraŋal napurruŋgal dhuwandja dhäwu nhokuŋ napurr dhu boŋguŋ bäki dhiyak research-gu djämaw? Wanhan nhokalnydja?

Yoram nhe dhu wo yaka'yun dhiyak research-gu djämaw?

Ŋuli nhe dhu yoram dhiyak research djämaw ŋunhi manymak, ga yalalaŋumirriy nhe dhu dhawaṯthun dhipuŋur research djämaŋur ŋunhiyiny nhokiyingala guyaŋanhawuylil?

Marrtjiny nhuŋu dhu boŋguŋ djämany nhuŋu dhiyakuwuy ŋunhi research-puynydja ŋunhi bäyŋun dhu wiripuŋuy Yolŋuy mal̪ŋ'maraŋ?

Marŋgi nhe ŋunhi dhiyal dhäwuŋur ga ŋorra gomurr-ḏal ga guŋga'yunhawuy dhukarr?

Yalalaŋumirriy ŋunhi nhe dhu napurruny ganarrthula walalnydja dhu djämamirriy mala dhäwu nhuŋu gurrupul gurruṯumirriwala mala nhokal.

Yalalaŋumirriy ŋuli nhe dhu marrtjin ganarrthula napurrunydja dhu marrtji ga ŋaŋ'thurr nhuŋu gurruṯumirriny mala nhä walalaŋguŋ guyaŋanhawuy ŋunhi nhe ga djäma napurruŋgal dhuwalatjan research djämakurr? Ga nhäkurr nhuŋu dhu djämapuy malanynha marrtji?

Participant		
Name	*Signature*	*Date*
…….	……	……
Independent Witness		
Name	*Signature*	*Date*
……	……	……
Interpreter		
Name	*Signature*	*Date*
……	……	……

Who should you contact to find out more?

If you have any questions about the study or if you wish to withdraw your consent at a later date, contact:

Stefanie Puszka (PhD student – Darwin):
Stefanie.Puszka@menzies.edu.au or Ph. 0401 301 204

Dr Katherine Curchin (supervisor – Canberra):
Katherine.Curchin@anu.edu.au or Ph. (02) 6125 4746

Living in Darwin for Dialysis Project

For Health Professionals and Policymakers

Participant Information Sheet (This is for you to keep)

hat is the research about?

study uses participant observation, story telling, interviews and documentary ysis to investigate medical relocation for renal dialysis amongst Yolŋu people End Stage Kidney Disease (ESKD). Experiences of relocation and the sition to urban life will be explored with ESKD patients who are relocating from ote communities to Darwin for treatment. It investigates access amongst Yolŋu ple with ESKD to food security, housing or accommodation and income support ne urban environment. The policy and service delivery context of dialysis and port services will also be explored with health professionals, support workers policymakers and through analysis of policy documents.

Who should you contact to find out more?

you have any questions about the study or if you wish to withdraw your consent at a later date, contact:

efanie Puszka (PhD student – Darwin):
efanie.Puszka@menzies.edu.au or Ph. 0401 301 204

Dr Katherine Curchin (supervisor – Canberra):
Katherine.Curchin@anu.edu.au or Ph. (02) 6125 4746

Who can participate?

s a component of the research I would like to speak with the following people:

- Public servants employed by the Northern Territory Government and Commonwealth Government in roles involved in developing policies addressing ESKD, coordinating dialysis services and administering funding for dialysis services and related infrastructure in the Northern Territory
- Members of the Northern Territory and Australian Parliaments and their staff who are involved in developing policy or advocating for the needs of Aboriginal and Torres Strait Islander people with ESKD in the Northern Territory
- Health professionals and support workers who provide care to Aboriginal and Torres Strait Islander people with ESKD in the Northern Territory

What will you be asked to do?

would like to interview you about your experiences and perspectives of oviding services or developing policies to address the needs of Aboriginal and rres Strait Islander people with ESKD. Interviews may take approximately one ur. With your consent, I would like to make an audio recording of the erview. I would also like to seek your consent to observe interactions between u and participating patients when I accompany them to pointments/treatment.

Who is conducting this research?

s research is being conducted by Stefanie szka as part of her PhD. It involves collaboration ween the Centre for Aboriginal Economic Policy search at the Australian National University and nzies School of Health Research at Charles win University. Members of the supervision nel are: Dr Katherine Curchin, Dr Caroline nuster, Prof Francesca Merlan (ANU); Prof Alan ss, Dr Paul Lawton (Menzies). This research is ded by the National Health and Medical search Council.

How many people are involved?

proximately 15 policymakers, 20 health fessionals and 4 – 8 Yolŋu family groups with a mber with ESKD will participate.

What are the risks and benefits?

All information provided in the course of interviews will remain confidential. This study will investigate the dialysis policy and service delivery context in an open, frank and constructive manner; while maintaining an understanding of the challenging environment in which policy development and service delivery takes place. It is possible that findings may recommend changes to existing policies and practice. Study recommendations may provide advice about ways in which changes to policy and practice can most effectively take place and how families can be engaged in services.

This project provides capacity development opportunities for Yolŋu co-researchers who are engaged to facilitate cross-cultural communication and interpretation of data. Informal capacity development opportunities are also provided to patients in navigating the urban environment if needed and desired.

Do I have to be involved in this study?

Participation is voluntary. Your decision about your involvement with this study will not impact on your relationship with Menzies School of Health Research.
You can refuse to answer any question. You can withdraw at any time, until final data analysis (June 2019).

/hat happens to your nformation?

tial findings will be shared with participants via nail prior to publication. Individually identifying formation such as the names of individual rticipants and job titles will not be published. ganisations involved in the study will also be de-entified where possible, however it will not be asible to de-identify dialysis services in Darwin.

ndings may be published in a discussion paper rmat targeted at policymakers and health ofessionals, as well as in a dissertation (thesis) and ademic journals. Findings may also be presented conferences.

you decide to withdraw prior to final analysis (June 19), your data will be withdrawn and securely sposed of.

l information will be stored in locked filing cabinets d password-protected computers at Menzies chool of Health Research. Information will be stored at Menzies School of Health Research for five years following publication and then moved to Menzies secure archives.

Ethical clearance for this research has been received from the Human Research Ethics Committee of the NT Department of Health and Menzies School of Health Research (ref 2017-2921), the Charles Darwin University Human Research Ethics Committee (ref H17133) and the Human Research Ethics Committee of the Australian National University (ref 2017/760).

If you wish to make a complaint about the conduct of this study contact:

The Human Research Ethics committee for the Department of Health and Menzies School of Health Research Ph: (08) 8946 8687 or (08) 8946 8692 or ethics@menzies.edu.au

Living in Darwin for Dialysis Project

Health Professionals and Policymakers Consent Form

(This form means you can say No)

I freely give my consent: (please tick Yes or No)

- To participate in a qualitative interview — Yes ☐ No ☐
- For my interview to be audio recorded — Yes ☐ No ☐
- For researchers to observe and make notes about interaction between myself and participating patients — Yes ☐ No ☐

By signing this form, I understand:

- The information provided about the study in the information sheet and from the researcher
- That the information I provide will be used in the research
- That it's OK to say NO to participation in this project and that if I say YES I can change my mind later.
- That all information I provide will be kept confidential.
- The possible benefits and risks of being involved.
- That if I pass away before the publication of findings, the researchers will consult with my next of kin to determine what should happen with my information.

Participant

Name	*Email*	*Phone*
…….	……	……
Organisation	*Signature*	*Date*
…….	……	……

Independent Witness

Name	*Signature*	*Date*
……	……	……

Who should you contact to find out more?

If you have any questions about the study or if you wish to withdraw your consent at a later date, contact:

Stefanie Puszka (PhD student – Darwin):
Stefanie.Puszka@menzies.edu.au or Ph. 0401 301 204
Dr Katherine Curchin (supervisor – Canberra):
Katherine.Curchin@anu.edu.au or Ph. (02) 6125 47