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A Transnational Syndemic: 
Cook Islanders and their experiences of TB and diabetes

Evelyn Marsters

A thesis submitted in fulfilment of the requirement for the degree of
Doctor of Philosophy in Development Studies, University of Auckland, August 2013
ABSTRACT

This thesis focuses on the influence transnationalism has upon the health of Cook Islanders. Central to this enquiry is the relationship between Cook Islanders’ population mobility and the unequal burden of diseases such as TB and type 2 diabetes. The research explores the contextual and mechanistic impact transnationalism has within the Cook Islands TB and type 2 diabetes syndemic. I argue that a syndemic orientation to health research allows potential health risks to be investigated within a constellation of interacting biological, socioeconomic, cultural and political conditions. From the outset, TB and diabetes are considered to interact in ways beyond the biological, and harmful social conditions, to act synergistically to increase the burden of disease.

This research is significant and timely because the type 2 diabetes epidemic has recently been acknowledged as a significant factor in accelerating the rate of TB globally, and in the Western Pacific region. In simple terms, TB triggers diabetes or when diabetes is already present, diabetes acts as a risk factor for the development of TB. The interaction between TB and diabetes poses a particular threat for the Cook Islands population given suspected high levels of latent TB within older cohorts of the population and existing high levels of type 2 diabetes. Although current case numbers of TB are low in the Cook Islands and among Cook Islanders in New Zealand, this thesis provides evidence that active transmission of TB does exist. Drawing on empirical qualitative data drawn from interviews and observation this research is able to conclude that poverty, poor nutrition, stigma, delayed diagnosis and household overcrowding are significant factors that act synergistically within this syndemic to exacerbate illness.

Central to this research are the health and mobility stories of Cook Islanders who have experienced either or both diseases. In order to capture the transnational behaviours and the possible implications they have for their health, participants were interviewed in multiple locations in New Zealand and the Cook Islands. Purposively transnational in design, this research incorporates the perspectives of Cook Islanders living in the Pacific Islands of Aitutaki and Rarotonga, and the metropolitan suburbs of Avondale, Otara, Glen Innes and Porirua. It explores the transnational social field with regards to health and health service access for Cook Islanders in each of these places. The complexities of health
and mobility stories lend themselves to narrative analysis and pictograms as a way of illustrating that a Cook Islands TB-diabetes-transnationalism syndemic exists.

That this syndemic exists leads to a discussion on the relationship between health, development and transnationalism. This debate throws light on the limitations of nation-centred approaches to health services and highlights both the linkages and gaps in health services for the Cook Islands population. By looking more deeply at the inherent connections between diseases it raises questions about the way in which health research is framed, who our research is for, and whether or not such a view is sustainable for the future.

Keywords: transnationalism, syndemics, New Zealand, Cook Islands, health, TB, type 2 diabetes
ACKNOWLEDGEMENTS

This research project would not have been possible without financial support from the Health Research Council of New Zealand and the University of Auckland. The ‘Transnational Health in the Pacific through the Lens of TB’ project provided the platform for this research and contributed to important contemporary understandings of transnational people in New Zealand and the Pacific. The project members provided me with both the knowledge and the confidence to undertake this study. Special thanks to Professor Julie Park, Associate Professor Judith Littleton, Sagaa Malua, Dr Jennifer Hand, Debbie Futter-Puati and Tufoua Panapa for providing the sounding board for my on-going conceptualisations of this research.

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Several organisations were instrumental in connecting me with interview participants and developing my contextual understanding of the research project. A huge thanks to the Ministry of Health in New Zealand and the Cook Islands, The Pacific Paramedical Training Centre, The Auckland District Health Board, Public Health Nurses Kathy, Metua and Teremona, and Social Welfare Officer Kitiona. I am also grateful for the Cook Islands Health Network Advocacy group for their support and assistance with the scoping phase of this research. Many thanks also to Damon Keen from 3 Bad Monkeys who provided the technical and design skills to transform my case studies, maps and conceptual figures into imagery. I would also like to acknowledge the copy editing work of Pauline Herbst.

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This degree represents just one of the ways I have grown as a person since meeting my husband Dylan. We work so well together that even the ridiculously challenging appears to be a fun opportunity. Thank you for understanding the importance of my work.

To my children, Abel Jackson and Nina Pearl, the spirit you bring to our family puts everything into perspective. Thank you for the distraction and the joy.

Lastly, this thesis is dedicated to a transnational health worker I met during my Master’s research in Mauke, the Cook Islands. Dr Colleen Lal from Myanmar worked extensively in the outer Cook Islands and has a deep respect and love for the Cook Islands people. She transformed many Cook Islanders lives, including my own. Thank you Aunty Colleen for sparking my interest in Cook Islands health and development.
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# LIST OF ABBREVIATIONS AND GLOSSARY

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<tr>
<td>ADB</td>
<td>Asian Development Bank</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>CDs</td>
<td>Communicable Disease</td>
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<tr>
<td>CDC</td>
<td>Centre for Disease Control</td>
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<td>CIHNA</td>
<td>Cook Islands Health Network Association</td>
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<td>DOTs</td>
<td>Directly Observed Therapy</td>
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<tr>
<td>Ei katu</td>
<td>Head garland</td>
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<tr>
<td>ERP</td>
<td>Economic Reform Process</td>
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<tr>
<td>Feeding child</td>
<td>Informal Cook Islands adoption. Refers to the “feeding” of children and the fostered children themselves.</td>
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<tr>
<td>GDM</td>
<td>Gestational Diabetes Mellitus</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>LTBI</td>
<td>Latent tuberculosis infection</td>
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<td>Maki Maro</td>
<td>Tuberculosis</td>
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<td>MDG</td>
<td>Millennium Development Goals</td>
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<tr>
<td>Mimi</td>
<td>Urinate</td>
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<tr>
<td>MOU</td>
<td>Memorandum of Understanding</td>
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<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
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<tr>
<td>NCDs</td>
<td>Non Communicable Disease</td>
</tr>
<tr>
<td>PACER-Plus</td>
<td>Pacific Agreement on Closer Economic Relations–Plus</td>
</tr>
<tr>
<td>Papa’a</td>
<td>Person of English or European Descent</td>
</tr>
<tr>
<td>PHNS</td>
<td>Public Health Nurses</td>
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<tr>
<td>PICs</td>
<td>Pacific Island Countries</td>
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<tr>
<td>SPC</td>
<td>Secretariat of the Pacific Community</td>
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<tr>
<td>TB</td>
<td>Tuberculosis Bacilli</td>
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<tr>
<td>TBD</td>
<td>Tuberculosis Bacilli Disease</td>
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<tr>
<td>Tutaka</td>
<td>Annual health check</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>Whakapapa/Akapapa’anga</td>
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CHAPTER ONE

Background to the research

This thesis reconceptualises and reframes health and development in a way that recognises connections between health conditions, diseases and the permeable boundaries which surround people’s lives. As Nichter argues:

Global health is a biopolitical agenda that involves the politics of an unnatural distribution of diseases and health care resources as well as the politics of transnational governance related to the control of emerging diseases and threats to global biosecurity and health as a human right (2008, p.151).

I argue that by addressing the “dynamic processes through which health disparities are created, maintained and changed” (Edberg et al. 2011, p.576), positive contributions to health and development interventions can be made. Tuberculosis (Kwan and Ernst 2011; Farmer 2000) and diabetes\(^1\) (Rock 2003) are diseases of poverty, and recently the diabetes epidemic has been acknowledged as a significant factor in accelerating the rate of TB globally (Restrepo et al. 2009). When these diseases are used as a research lens, they reveal how “multiple biological factors intersect and interact to increase disease susceptibility or burden, as well as bio-political pathways in which social and structural factors interact with biological factors to produce a greater disease risk and burden” (Ostrach and Singer 2012, p.259). The reframing of diseases and associated health conditions existing within active constellations of synergistic variables prioritises the interplay of biological, social, cultural, economic and political forces at play. The application of a syndemic framework within this thesis will reveal that adverse social and economic conditions can affect or worsen the biological conditions of TB and diabetes.

Syndemic theory and its applications are relatively recent on the health research scene both in developed and developing countries. Since the late 1990s this theory has provided researchers with tools to explore the “multiple reinforcing conditions” that synergistically interact and result in the burden of disease (Singer and Clair 2003). Syndemic theory sets aside the biomedical explanation of disease as a discrete, clinically identifiable entity.

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\(^1\) The term diabetes is used within this thesis to refer to type 2 diabetes mellitus or adult onset and non-insulin dependent diabetes mellitus.
As Singer and Clair assert, syndemic diseases are “sustained in a community/population because of harmful social conditions and injurious social connections” (emphasis in original 2003, p.429). Mendenhall recently suggested that studying syndemic interactions necessitates “three rules”:

The clustering of two diseases exists within a specific population; fundamental contextual and social factors are co-constructed with that cluster; and the disease cluster creates the potential for adverse disease interaction, increasing the burden of populations (2012, p.13).

The fundamental contextual factor in this syndemic study is the transnational behaviour of Cook Islanders. According to Vertovec (2004), transnationalism recognises that concepts of identity, citizenship, borders, place and economy are, for some people, fluid across space and through time. Therefore in order to capture the transnational behaviour of these peoples’ lives and the possible implications this has for health, multi-sited participants in New Zealand and the Cook Islands engaged in the project. I propose that Cook Islanders’ transnational behaviour can be seen to interact with TB and diabetes within a syndemic framework. The additive interplay (Stall et al. 2003) of multiple health problems and the significance of social conditions in different geographical locations that foster disease clustering (Singer 2009), are prioritised within this study. Syndemic theory, which has its roots in medical anthropology, also uses epidemiological, spatial and biological forms of data collection, analysis and statistical modelling (Singer et al. 2011). My decision to use this framework committed me to what Bastia, Fisher, Holland and Holtom describe as “a desire to be innovative and to use different types of methods appropriate to different contexts” (2005, p.237). Indeed, syndemic theory encourages researchers, practitioners and policy makers to step out of silos and towards systems-based “big picture” awareness of disease (Singer 2009).

This thesis argues that the Cook Islands TB and diabetes syndemic throws light on the limitations of nation centred approaches to health services and highlights both the linkages and gaps in health services for the Cook Islands population. By looking more deeply at the inherent connections between diseases, both in the home country and in New Zealand, questions begin to surface about the way in which our health research is framed, who our research is for, and whether or not such a view is sustainable for the future. Lee proposes that we need fresh analytical approaches which acknowledge that “the delineation between
the winners and the losers of globalisation cut across national boundaries and can become invisible when concentrating on aggregated data or national averages” (2004, p.15). In this thesis, I question both how we construct health research, and how we deliver health services. I focus on the connections between diseases and harmful social conditions within a transnational population in an attempt to suggest more appropriate health services. As such this thesis deals with the double burden of Non Communicable Diseases (NCDs) and Communicable Diseases (CDs) in the Pacific as well as this crisis in the Pacific population in New Zealand.

TB as a lens

This thesis is one contribution to a wider multi-disciplinary study concerned with the relationship between the interconnections and frequent movement of Pacific people and health inequalities. The study, titled ‘Transnational Health in the Pacific through the Lens of TB’ uses TB to explore the different socio economic and life course processes on health over time and space. The case study countries included in this wider study are Tuvalu and the Cook Islands and include Tuvaluan and Cook Islands populations living in New Zealand. This study is situated at the University of Auckland, and includes researchers and students from multiple disciplines and countries. A key characteristic of the wider study is that all research concerning the case study locations is led by country specialists and student research is conducted by people with prior experience and commitment to the islands. One of the guiding motivations of the study is to position TB as a historical and contemporary significant health issue in the Pacific region. The “Transnational Health in the Pacific through the Lens of TB” project demonstrates a continued interest in the socio-economic characteristics of the disease and how it affects certain populations. For example, by raising socio economic issues as important factors impacting on the rate of TB, Prior signals the suitability of using TB as a lens into the interconnectivity of factors which contribute to health inequity:

The impact of tuberculosis in the Pacific depended not only on infection with the tubercle bacillus but also on factors such as deterioration in housing, overcrowding, changing diet and the effects of alcohol. It is likely that tuberculosis contributed to the dramatic decline in population that was universal throughout the Pacific in the fifty to one hundred years following the opening up of this vast area (Prior 1989, p.150).
Prior’s (1989) study made a significant contribution to health research in the Pacific by placing high levels of movement in this region alongside socio-economic factors as influential in health outcomes. What Prior (1989) refers to as an ‘opening up of this vast area’ created an environment where whole populations became vulnerable to new diseases that accompanied the processes of trade and colonialism in the Pacific.

Contemporary research in this field is still searching for the reasons behind the prevailing factors of health inequalities for Pacific peoples (Baker et al. 2000; Baker et al. 2008; Littleton and Park 2009; O’Connor et al. 2009; Voss et al. 2006). There are also vast differences in the types of health issues prioritised in different parts of the region. This study draws upon research concerning the connections between Eastern Pacific countries and metropolitan cities in New Zealand where uneven development and the clustering of health conditions can be attributed to diverse patterns of population mobility (Barcham et al. 2009; Hau’ofa 1993; Liki 2009; Lilomiava-Doktor 2009) overcrowding, changes in diet and lifestyle behaviours (Baker et al. 2000; Dunsford et al. 2011; Milne and Kearns 1999; Tukuitonga and Finau 1997).

Infectious diseases such as TB are commonly associated with places of extreme poverty in undeveloped pockets of the world, as well as poor areas and marginalised populations in the developed world. This research will highlight that the historical lineages that connect the Cook Islands and New Zealand have produced a situation whereby this unequal distribution of disease can be seen in both countries. Yamin argues that contemporary approaches to health must enable and empower people and that “we require a conception of rights and obligations that locates us all on the same political map and connects the dots” (2010, p.12). Heeding this call for action, this research places the Cook Islands population within a transnational social field, and is pursued via multi-sited ethnographic methods (Marcus 1995). Close attention has been paid to the “cracks and fissures” of development (McGregor 2009, p.1695) within the transnational social field and the resulting negative effect these have on Cook Islanders’ health. At the same time, the common and connecting forces which contribute to this emerging syndemic are elucidated.
Why diabetes?

Viney et al. (2011) argue that diabetes is one of the key emerging risk factors for TB in the Pacific region. ‘The Regional Strategy to Stop Tuberculosis in the Western Pacific 2011-2015’ highlights the emerging challenges to lowering TB prevalence as high levels of migration, aging, tobacco use, diabetes and infectious patients not seeking care. The challenges identified by the World Health Organisation (WHO) reflect my own interest in the interaction of economic and political inequality, and heath (Farmer 2000, Rock 2003). Diabetes, when viewed as synergistically interacting with TB provides a window into other socio-economic and cultural influences upon people’s health. Mendenhall argues that the “Curious global pattern of diabetes distribution provide some insight into the role played by political-economic and social processes in the diabetes problem” (2012, p.18). Whilst she positions diabetes as synergistically interacting with depression and social distress, I argue that diabetes interacts with TB among a transnational population. The transnational orientation of this research is guided by my own New Zealand born Cook Islands heritage and health and migration studies like the Tokelau Island Migrant Study (Prior 1989). The Tokelau Island Migrant Study entailed research conducted in Tokelau and New Zealand, taking into account the complexities of health outcomes among migrant populations in both ‘home’ and ‘away’ settings and using measurements of blood pressure to assess the health consequences of migration to a western society (Salmond, Joseph, Prior, Stanley and Wessen 1985). The appeal of transnational studies is the ability to capture multiple dimensions of change for multiple communities which have migrated. As Macpherson and Macpherson argue in reference to Samoan migration:

It has extended the global reach of families and villages, and, in the process has changed each of them in fundamental ways; both entities would be very different had this flow of people not occurred (2009, p.59).

As my own research has progressed since 2009, research on the “double burden” of TB and diabetes has increased however, Harries et al. assert that “many critical questions regarding the association between diabetes mellitus and TB remain unanswered because of either poorly conducted studies or no studies at all” (2012, p.662). One response to this call for further research in this area is the Secretariat of the Pacific Community (SPC) driven collaborative research project on TB and diabetes in the Pacific region (World Diabetes
Foundation 2013). In summary, this project aims to estimate the burden of this ‘double burden’ across the Western Pacific and to make changes to testing, diagnosis and treatment procedures in light of this co epidemic.

The research question

*What are the relationships between TB, diabetes and transnationalism within the Cook Islands population?*

This study rises to the challenge of conceptualising health research in a way which accounts for the fluid and dynamic livelihoods of Cook Islanders. As a group of people, Cook Islanders live across many boundaries with atoll, island, and national borders actively navigated for reasons such as education, employment, celebrations, ceremonies and health (Alexeyeff 2008; Koteka-Wright 2007; Horan 2012; Marsters et al. 2006; Underhill 1989). For example, Loomis differentiates the Cook Islands migratory experience from other Pacific peoples:

> Cook Islanders have been migrating to New Zealand in increasing numbers since World War 2. Unlike many Pacific migrants, they are citizens of New Zealand and thus have rights of entry (1990, p.61).

Loomis signals the importance of placing more attention upon the pathways and linkages between migrants in the Pacific islands and in metropolitan cities (Loomis 1990, p.68). The increasing numbers of Cook Islanders in New Zealand over time has created a transnational social field which I believe is an important factor in Cook Islanders’ health, and their search for health services. The search for these health services becomes an issue of inequality when Cook Islanders’ health experiences are uneven, and dependent upon their economic status, cultural status and where within the Cook Islands or New Zealand. This thesis explores the contribution transnationalism makes to Cook Islanders’ level of health, their perceptions of health and their access to health service. In doing so, a range of political and socio-economic factors are brought to light and seen to interact with TB and diabetes. The accounts of Cook Islanders within this thesis challenge “bounded and territorial” understandings of colonialism (Kothari 2012) and the “quasi-colonial status” experiences (Murray and Overton 2011) of living with disease.

This research is situated across international, national, regional, metropolitan, interisland and village boundaries because these are the beginning points of Cook Islanders travels.
The methodology and the data collected are situated within a transnational social field. The topic of TB and diabetes in this study are used to provide alternative conceptualisations of existing and potential health threats. In combination, the ideas of transnationalism included within a syndemic research project provide a vehicle to explore how health relates to transnationalism, and how transnationalism relates to health.

The aims of this research are:

1. To isolate specific examples of how transnationalism and transnational behaviours affect the health of Cook Islanders.
2. To state the current level of existence and potential threat of the TB and diabetes syndemic for Cook Islanders.
3. To demonstrate that syndemic theory can positively contribute to our understanding of disease and health and development research.
4. To raise questions about nation-bounded responses to health service delivery and interventions.

Research participants

Key characteristics of the Cook Islands population in New Zealand\(^2\) and in the Cook Islands signalled the suitability for their inclusion within this research. In the following sections statistics are provided which indicate that many Cook Islanders in both countries live in vulnerable situations based upon their low levels of education, employment in low paid, unskilled industries, household size and lack of property ownership. These statistics provide one of the many contextual layers of this research. It is not my intention to negatively frame the Cook Islands population, but to instead provide some evidence of the types of deprivation experienced. Furthermore, one of the limitations to providing this overview is that the data is not easily aligned, due to census design and census dates being country specific. As an example of the difficulty in ascertaining relevant mobility statistics for Cook Islanders, the mobility of Cook Islanders between the islands and internationally can only be captured at five year intervals by ‘usual resident five years ago’ (Statistics New Zealand 2007). In this way, because Cook Islanders could have made several journeys in

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\(^2\) This refers to people self-identifying as Cook Islanders in the NZ census.
between this time frame, this study draws on the interview data (see chapter six and seven) to substantiate this study’s claim of high levels of population mobility and the existence of a transnational social field (see chapter two).

**Cook Islanders in New Zealand**

In New Zealand, the Cook Islands population is the second largest Pacific ethnic group and in 2006, 58,011 Cook Islanders were resident in New Zealand (Statistics New Zealand 2007). The Cook Islands population is young, growing, and mostly New Zealand born (73%). Multi-family households are more common for Cook Islanders (12.5%) living in New Zealand than the members of the wider population, indicating a high degree of overcrowded living conditions (Statistics New Zealand 2007). Cook Islanders are also less educated\(^3\) and within the New Zealand labour force Cook Islanders work mostly as labourers (23%), machinery operators and drivers (14%), and trade workers (13%). Over a third (37%) of Cook Islanders in New Zealand resides in Housing New Zealand Corporation accommodation.

Between 2010 and 2011 there were seven new cases of Cook Islanders with TB. During this period, Cook Islanders represented 2.3% of new TB cases in New Zealand (Institute of Environmental Science and Research 2012). Cook Islanders in New Zealand like other Pacific peoples experience disproportionate burden of diabetes and renal failure. Between 2011 and 2012, the Ministry of Health recorded over 1,574\(^4\) Cook Islanders hospitalised because of their diabetes. During the same period 1,069 Cook Islanders were discharged from a hospital because of renal failure or dependence upon dialysis.

**Cook Islanders in the Cook Islands**

In 2011 there were 14,974 people recorded as usually resident in the Cook Islands. Cook Islanders in the Cook Islands are distributed across 15 islands and atolls which are geographically divided into a Southern and Northern Group. There are differences in

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\(^3\) The adult Cook Islands Maori in New Zealand had a lower rate of formal qualifications of 55% compared to the total Pacific and total New Zealand Populations of 65% and 75% respectively.

\(^4\) Actual numbers of Cook Islanders in New Zealand who are diabetic are difficult to substantiate and indicators usually rely on data recorded via hospital admissions. The actual numbers of Cook Islanders undergoing treatment for diabetes is much higher, however, in this respect the Cook Islands statistics are usually agglomerated with other Pacific peoples.
cultural, social and economic activities between each of the islands (Ministry of Finance and Economic Management 2012). Sissons argues that:

Represented on the national flag, the Cook Islands is a circle of 15 stars, all of equal status and linked in perfect harmony. Represented on a map however, the country appears as a widely scattered group of islands roughly divided into two groups (1999, p.11).

**Figure 1**: Map of the Cook Islands

The differences between the 15 islands are distinctive and over time, as Rarotonga has become more monetised and become the centre of flows of people, capital and ideas an unequal pattern of development exists in the Cook Islands (Loomis 1990; Marsters 2004; Sissons 1999). The different livelihoods which exist across the Cook Islands and for those Cook Islanders abroad are a real challenge for research, policy and development. It is difficult to get a sense of the disparities which exist across the transnational social field for
Cook Islanders, given that the most populous, economic and political islands receive the majority of attention. Access to the more remote Cook Islands remains a key obstacle for research and the delivery of health programmes. In this study, the islands of Rarotonga and Aitutaki were selected as research sites. Rarotonga (13,095 people) and Aitutaki (2,038 people) are the most populated and easily accessible islands in the Cook Islands. It should be noted that the accessibility options for Rarotongans and Aitutakians are distinct from those living on the smaller and more remote islands in the Cook Islands. Overall, the distribution of the total population was recorded in 2011 as 74% living in Rarotonga, 20% living in the Southern Group Islands and 6% living in the Northern Group islands (Ministry of Finance and Economic Management 2012).

The socio-demographic profile of Cook Islanders living in the Cook Islands is also influenced by mobility patterns. For example, the age distribution of Cook Islanders illustrates an outward migration between the ages of 15–29. And while most Cook Islanders (55%) were born in the village where they currently reside, 19% were born elsewhere in the Cook Islands and 26 % were born overseas (Ministry of Finance and Economic Management 2012). Education is free in the Cook Islands until the age of 15, and most children complete this level of education. Beyond this however, only 24% of the population over 15 have a trade, vocational or professional qualification (Ministry of Finance and Economic Management 2008). The occupational opportunities in the Cook Islands are limited into three major groups, where the majority of the population finds employment. The biggest occupational group for the employed resident population was in the category of Service Workers, Shop and Sales Workers (21%) followed by Elementary Occupations (16%) and Corporate and General Managers (14%) (Ministry of Finance and Economic Management 2012).

In a recent country profile undertaken by the WHO (2011), the leading causes of morbidity and mortality in the Cook Islands are NCDs. The report refers to an earlier piece of research

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5 Although outside the scope of my research, the health disparities of Cook Islanders living in the Northern Group do warrant further investigation. My Master’s research was conducted in Manihiki, and I was aware of the prevailing issue of access to secondary health services during this time.
carried out in 2001 that measured diabetes\textsuperscript{6} prevalence as 11\% in adult males and 3.8\% for adult females. According to hospital records across the Cook Islands, 16\% of all patients reported having hypertension and diabetes and 21\% diabetes only. The recorded case numbers of TB in the Cook Islands over the last decade has hovered between one-two cases per year (Viney et al. 2011).

**Cook Islands research participants**

Between June 2010 and October 2012 I performed interviews and observed Cook Islanders and health specific places. Research was carried out in the suburbs of Glen Innes, Otara and Avondale in Auckland; Cannons Creek in Porirua; Rarotonga; and Aitutaki. The term ‘participant’ is used as an umbrella term for people who were interviewed during this research. My main priority was to include the perspectives of people with recent experiences of either TB or diabetes or both diseases. Therefore, participants with experiences occurring after 2000 were selected to dovetail with the previous historical TB research conducted in the Cook Islands (Futter-Puati 2010). It should be noted however, when discussing diabetes with a participant; historical TB would come into the discussion and is therefore included in this study. The diabetes history of participants with TB was also explored. I interviewed 19 participants with disease experiences. I revisited 11 of these participants and conducted multiple interviews. Participants also include public health nurses (5); doctors (3); pharmacist (1); lab technicians (6); Pacific development specialist (1); government policy employees for the Cook Islands Government (3); community representative for Pukapuka association in New Auckland (1); and a social welfare officer in Porirua (1). The majority of participants were over the age of 40. This is because diabetes usually occurs later in life, and those in official or clinical positions were also over 40. Young men around 20 were also interviewed. There were 21 male participants, and 19 female participants.

\textsuperscript{6} During the Cook Islands Health Conference in 2013, a delegate from the WHO reported that the prevalence of obesity amongst the adult (over 20 years) population in the Cook Islands was between 65–70\% of the population. This is one of the highest in the Pacific region.
Thesis structure

In the first part of this thesis, the Cook Islands and Cook Islanders relationships with New Zealand is explained in more detail. In chapter two the theory of transnationalism is used to position the Cook Islands and New Zealand as part of an international interest in the different forms, practices and meanings of transnationalism. In particular, the second chapter situates the relationship between transnationalism and health particular to Cook Islanders. Central to this relationship is the role that colonialism and contemporary political relationships have upon the health of Cook Islanders. Chapter three introduces the research framework of syndemics. Syndemics is used in the thesis for its ability to pay close attention to the interactions and synergistic variables that can produce ill health for certain populations (Singer 2009). In chapter four the research story and the trials and tribulations that accompanied this research design are presented in the method and methodology section. Also included in chapter four is discussion on ethical research across the transnational social field.

Once the research context, research design, and research experience has been set up the remainder of the thesis is dedicated to the presentation and analysis of the research results. Chapter five begins this process by conceptualising a syndemic framework in light of the material collected and the high level findings are explored via case studies, which have been illustrated in an attempt to highlight the significant factors and key events that structure the syndemic. These illustrated case studies were designed with the assistance of a graphic illustrator (Damon Keen) as a way to bring to life the myriad of complex connections that exacerbate the experiences of disease for Cook Islands’ participants. The analysis then shifts to narrative analysis of key factors isolated as significant variables in the TB, diabetes and transnationalism syndemic in the Cook Islands population. The case studies and narrative analysis chapters provide a way to test the strength of the syndemic connections and highlight the Cook Islands specific vulnerabilities to the syndemic.

Syndemic theory holds some promise for the future of health research, and the application of further possibilities for these types of frameworks in development work is also considered in the second half of the thesis. In chapter six, the methods used within this research are argued to have strength in their ability to thread together political history, patterns of livelihoods across transnational space, disease, and socio-economic and cultural
conditions, to produce definite statements on the existence and potential threat of syndemics. The enquiry in chapter six runs through the issues of diagnosis, food and nutrition and the different aspects of stigma manifesting in the syndemic. In chapter seven I attempt to clarify the role that transnationalism plays upon the health of Cook Islanders. In the conclusion, chapter eight, I attempt to bring together the contextual and analytical components of the research. This is done to demonstrate the strength of the research design and to throw light on the possibilities of syndemic research in the area of health and development.
CHAPTER TWO

New Zealand, the Cook Islands and Cook Islanders

This chapter introduces the density of historical and contemporary relationships between the Cook Islands and New Zealand. It is argued that the formation of these relationships over time and the orchestration of key structural changes by government and organisations outside of the Cook Islands have impacted upon employment and the subsequent population mobility of Cook Islanders. The chapter begins by locating these relationships in a historical sense. The chapter then progresses to new understandings of Cook Islanders made possible via the literature on health and development and the theoretical concept of transnationalism.

Figure 2: The Cook Islanders, the Cook Islands and New Zealand

The sites of this research and the scale of population of Cook Islanders in New Zealand as a result of population growth and depopulation in the Cook Islands are illustrated in Figure 2. Currently, more Cook Islanders reside in New Zealand than the Cook Islands, a pattern which can be traced back to the rising number of Cook Islanders migrating to New Zealand
after the Second World War (Loomis 1990; Macpherson 2012). During this period, Cook Islanders were attracted to New Zealand for employment opportunities in primary and manufacturing industries (Macpherson 2012). However, Cook Islanders had been present in New Zealand since the nineteenth century (Bertram 2012). Mallon refers to early movement of Pacific people between the islands, New Zealand and elsewhere, as “regional traffic” (2012, p.92) conveying not only the establishment of main thoroughfares between the Pacific Islands and New Zealand, but also disrupting the notion that New Zealand only became connected to the Pacific through the migration of the 1960s and 1980s.

Nevertheless, the movement of Cook Islanders during the 1960s and 1970s, facilitated by a newly opened international airport in 1974, led to growth of Cook Islands communities resident in New Zealand and large scale depopulation in the Cook Islands (Barcham et al. 2009; Crocombe 2003; Koteka-Wright 2007; Spoonley 2001). The opening of this airport is also significant for facilitating access of health services in New Zealand for Cook Islanders. Another key moment in political history which heavily influenced large scale migration from the Cook Islands to New Zealand was in the 1990s when economic restructuring in the Cook Islands halved public sector jobs and removed government subsidies for basic goods and services (Murray and Overton 2011; Secretariat of the Pacific Community 2005). For example, in 1995 the Asian Development Bank (ADB) signed a Memorandum of Understanding (MOU) with the Cook Islands government providing them with the responsibility of investigating the economic situation of the nation. The Cook Islands had, at this time been unable to meet international loan repayments and pay public servants and other creditors. The ADB, as a major lender of development finance to the Cook Islands, along with other aid donors refused payments to the government until an investigation had taken place (Rasmussen 1998). During this investigation, which lasted a year, it was discovered by the ADB that development programmes had been overly ambitious, funding aid had declined from New Zealand and costs associated with an inflated public service were high (Asian Development Bank 1995). The solution, according to the ADB was a restructuring ‘rescue’ package that mirrored the economic reforms implemented in New Zealand from 1984–1993. The package, termed the ‘Economic Reform Process’ (ERP), was designed by representatives from the ADB, New Zealand and the Cook Islands. The overall aim was to reduce numbers government employees, by shifting towards ‘user pays’ for
public services, enhancing government accountability and stimulating private sector investment (Asia Development Bank 1995; Pragnall 2003). The implementation of the ERP, which is referred to within the Cook Islands by the local population as ‘the Transition’, was funded by another loan from the ADB (Pragnall 2003).

The economic restructuring in the Cook Islands, part of the neo-liberal economic development of the 1990s, influenced population decline in the Cook Islands in both the Southern and Northern groups. Murray and Overton in the description below capture some of the intensity of this period of time for Cook Islanders as:

... a very rapid and harsh structural adjustment. New Zealand, its (Cook Islands) former colonial power, in concert with the Asian Development Bank, imposed a severe cut in direct budgetary support for the Cook Islands government in 1996. As a result nearly two thirds of the country’s civil servants lost their jobs more or less overnight (2011, p.276).

‘The Transition’ is considered within this research as an important moment in time contributing to the existing Cook Islands transnational social field. According to Spoonley, Bedford and Macpherson:

Without doubt, the circulation of people, capital, goods and ideas all represent important transnational linkages that have contributed to the development of Pacific peoples in their island homes and ‘homes abroad’. However, the 1980s and 1990s have also marked an important period of economic adjustment as states have sought to respond to new global forms of capitalist production and consumption, often by radical measures. In the case of Pacific peoples, this restructuring has led to new or enhanced forms of impoverishment (2003, p.39).

In terms of impoverishment or declining opportunities, this research expands the analysis of structural change in the Cook Islands in the 1990s to include Cook Islanders whose health and mobility experiences changed as a result of the transition. In some cases, the responses of Cook Islanders to global forces have been positive, with the creation of transnational communities as one example (Dunsford et al. 2011; Nahkid 2009). However, these communities have heterogeneous sets of transnational behaviours and activities (Dunsford et al. 2011) and as far as this research is concerned, what makes these sets of practices distinctive is that they are heavily influenced by Cook Islanders’ New Zealand citizenship and access to health and social services in multiple countries. This research
demonstrates that access to these services is not seamless across the transnational social field instead, Cook Islanders have designed sets of practices and strategies which can be seen to both positively and negatively influence health.

**The history behind contemporary Cook Islands health relationships**

The colonial relationships between the Cook Islands and New Zealand occurred during a period where New Zealand was becoming responsible for administration in the Pacific Territories at the beginning of the twentieth century. During this time, New Zealand took over as the colonial power in many parts of the Pacific, including the Cook Islands and Niue in 1901 (Crocombe 1979). A colonial government remained in the Cook Islands until 1964 when self-government was discussed, planned and approved at the Sessions of the Cook Islands Assembly and by the New Zealand Parliament (Crocombe 1979; Strickland 1979). This constitution was initiated by the New Zealand government during a period where colonial administrations in the Pacific were retreating, and the self-determination of indigenous populations was heavily promoted by organisations such as the United Nations (UN). Strickland (1979) argued that many Cook Islanders believed that this was the:

... opportunity to recreate nationhood in the Cook Islands and to ensure that the governance of the Cook Islands was in the hands of men and women dedicated to the cause of greater prosperity and increased social welfare of the Cook Islands (p.9).

The Cook Islands and New Zealand also recognised that the Cook Islands would have difficulty in sustaining a fully independent national state at such a small scale (Strickland 1979). The response of both governments was for the Cook Islands to be in ‘Free Association’ with New Zealand. Free Association represents an alternative to independence that allows Cook Islanders to govern their own islands and have full responsibility for external affairs. It also allowed Cook Islanders to retain New Zealand citizenship, use New Zealand currency, and to call upon the New Zealand government to assist in defence and foreign affairs matters (New Zealand Government 1999). One of the most significant features of the Free Association relationship is that it continues to afford Cook Islanders the advantage of New Zealand citizenship. Spoonley et al. assert that this is one example of how New Zealand has a characteristically “soft” approach to citizenship. Furthermore the authors state that:
The state (New Zealand) has sanctioned multiple official identities and loyalties (e.g. dual citizenship, generous provisions in the case of legal residency, joint residency and benefits with other countries, most notably Australia), and this has provided a platform for transnationalism (Spoonley et al. 2003, p.41).

Free Association between the Cook Islands and New Zealand plays a role in not only the population mobility of Cook Islanders, but also their access to social welfare and other benefits while in New Zealand. Free Association has been carefully protected by successive Cook Islands governments (Sissons 1998) but how Free Association translates to the daily lives of people living with disease is worthy of further investigation. Moreover, more recently, scholars are suggesting that international agreements such as Free Association reflect the negative influence the colonial authority exerts in the Pacific region (Banks and McGregor 2011; Murray and Overton 2011; Teaiwa 2012). For Cook Islanders, as well as other Pacific peoples, Teaiwa argues that:

...citizenship complicates and subverts notions of kinship in the context of New Zealand’s status as a colonial authority in the Pacific (2012, p.257).

Free Association has become a taken for granted, positive outcome of the historical colonial relationship by both New Zealand and the Cook Islands. This study provides further understanding of how Cook Islanders navigate the complicated networks created by this relationship. This thesis attempts to contextualise the way in which Cook Islanders navigate these colonial pathways via citizenship to New Zealand. The issue of how colonial authority is expressed with regards to the health of Cook Islanders is touched upon, however, further research in this area is needed.

The pattern of Cook Islands’ population mobility rests upon the Free Association arrangement allowing Cook Islanders to engage in complex transnational networks. This study intends to prove that Cook Islanders’ population mobility complicates the functioning of state welfare and health care across two countries. The research also provides examples of Cook Islanders experiencing a range of cultural, commercial and social practices influenced by both their immediate surroundings and people and places elsewhere. As Crocombe describes “Cook Islanders of today are genetically and culturally new people, creating new culture, deriving from the past and present, the local and the international”
The question remains, what implication does this have for the health of the Cook Islands population?

**Contemporary health ‘partnerships’**

This research addresses a range of social and biological constructions of health. These constructions are understood to exist within an active transnational social field of both personal and political relationships. Whilst the importance of politics and health is a wide topic of discussion, to date, there is no clear demonstration how this relationship has manifested in the Pacific. For example, in 1989 Salmond et al. reflexively asserted that the key limitation in the Tokelau Islands Migrant Study was not realising the “concomitant changes within both originating and host societies superimposed upon migration experiences” (p.45). Cartwright (2011) also argues that “different immigration statuses create particular local biologies embedded in the structural violence of powerlessness and lost life potentials” (p.475). This study proposes that transnationalism provides a better picture of how health moves across political and physical boundaries.

One of the most significant contemporary health relationships between the Cook Islands (Rarotonga) and New Zealand (Manukau) is the Memorandum of Understanding (MOU) between the Cook Islands Ministry of Health and the Counties Manukau District Health Board. This document states that:

> A new health cooperation arrangement between New Zealand and the Cook Islands aims to develop the capacity and capability of Te Marae Ora: The Ministry of Health Cook Islands. This initiative builds on the already close links and free flow of people between the Cook Islands and New Zealand. Cook Islanders are New Zealand citizens and if they travel to New Zealand they are entitled to publicly funded services. This impacts on New Zealand’s health system and also creates a role for New Zealand to address health issues in the wider region, such as the development of the health workforce (Cook Islands Ministry of Health and Counties Manukau District Health Board 2009, p.9).

On the surface, this relationship appears like a logical step to address the health needs of Cook Islanders in both countries. It also signals a realisation that the health of Cook Islanders is tied to the political agendas of both countries. The MOU, as a response to formalising the flow of patients from Rarotonga Hospital to Middlemore Hospital, does not recognise the different categories of Cook Islanders travelling to New Zealand for health
services. Referrals to Auckland health services are offered to Cook Islanders in the Cook Islands, and paid by the government if a decision is made by clinical staff for secondary or tertiary care overseas. However, many more Cook Islanders make the choice to seek health services in Auckland of their own accord. Whilst the services may be publically funded because of their citizenship, their transfers, accommodation and support are paid with personal funds. In this way, the MOU is limited because it does not recognise that Cook Islanders’ entitlement to publically funded services is not seamless but instead encompasses complex decision making processes at private and public levels.

The MOU between the Ministry of Health in the Cook Islands and the Manukau District Health Board does, however, rightly recognise that Cook islanders may access health care in multiple locations. Unfortunately the description of these movements does not unpack the differential health access experiences of Cook Islanders living outside the Rarotonga - Counties Manukau nexus. However for Cook Islanders, health access experiences depend upon proximity to the international airport, the main hospital in Rarotonga, and financial resources. The Memorandum of Understanding states:

> It is recognised that the Cook Islands people frequently travel between the Cook Islands and New Zealand on a regular basis and that often, health services in the Cook Islands and the Counties Manukau are involved in the provision of health care to the same individuals and families (Cook Islands Ministry of Health and Counties Manukau District Health Board 2009, p.2).

On a more explicit level, The Memorandum of Understanding aims to improve the health outcomes of Cook Islanders in both locations through a series of activities. The key collaborative activity is the proposed development of “processes and referral pathways”. These are thought to be able to enhance the provision of care to Cook Islands’ residents requiring treatment within services in Manukau District Health Board (Cook Islands Ministry of Health and Counties Manukau District Health Board 2009).

It is important to clarify how access to health care differs for Cook Islanders in either country. Eligibility for health services rests on the residency status of the patient. Under the Citizen Act of 1977, Cook Islanders are eligible for publically funded health and disability services. Time spent overseas does not affect New Zealand citizens’ eligibility. If a Cook Islander arrives in New Zealand for the first time they can access health services.
However, if only temporarily in New Zealand, they may not meet the requirements for primary health organisation enrolment. Furthermore, if a New Zealand resident Cook Islander were to find themselves in the Cook Islands under this status during a moment of mobility, a government paid referral option back to New Zealand is not available to them. The cost of transport to New Zealand will be borne by the family. The same category used to distinguish patients exists in New Zealand. This reveals that while Cook Islands transnationalism may appear to be boundless in terms of accessing healthcare, real barriers exist to Cook Islanders in both settings. The framing of health accessibility in terms of residency status also raises questions about citizenship and which state is the guarantor of rights (Cartwright 2011).

Other forms of transnational health relationships which are provided for within New Zealand’s aid budget include medical specialists visiting Rarotonga (and sometimes other outer islands) to provide services not usually available, as well as screening and diagnostic support. On a less formal level, collegial relationships between the doctors in the Cook Islands and New Zealand during periods of schooling, conferences or regional meetings also provide a range of support mechanisms for the doctors in the Cook Islands. Support, advice and assistance are often sought over the phone or internet when local information sources cannot solve the problem at hand.

These arrangements are evident within the context of both TB and diabetes. With regards to TB, assistance and diagnostic quality assurance is set up through the Pacific Paramedic Training Organisation, and random samples are sent to Wellington for assessment of the laboratory’s capability in Rarotonga. This organisation also provides the training for the majority of the Cook Islands’ laboratory technicians. The system of identifying, testing and treating TB cases in the Cook Islands is similar to New Zealand and the nurses in the Cook Islands are occasionally offered the opportunity to receive training with the TB Public Health Nurses (PHNs) in Auckland. With regards to diabetes, specialists working in the area of associated health conditions such as foot and eye disease also visit the Cook Islands periodically. If these specialists cannot make it to the outer islands, arrangements are made so that the patients can be resident in Rarotonga when the specialists are on the island. It is important to note that patients in the Cook Islands with renal issues are sent to, and become dependent upon the New Zealand health system on a permanent level.
Pacific and New Zealand “health”

This next section draws attention to the position of both the Cook Islands and New Zealand in the context of global development. This study suggests that pockets of deprivation experienced by Cook Islanders and other Pacific peoples in New Zealand and Australia are also part of Pacific development issues. For example, in Polynesia it is often said that infectious diseases are now in the background, and that the threat is the rapid increase of non-communicable diseases (NCD) and movement of NCDs into the younger cohorts (Taylor, Bampton and Lopez 2005). According to Taylor, Lewis and Levy, the shift towards non-communicable diseases in the Pacific is strongly associated with the introduction of western medicine in the 1950s.

The 1950s also saw the introduction and use of powerful antibiotics and other chemotherapeutic agents which would interrupt transmission of endemic diseases such as yaws, filariasis, and tuberculosis and were useful for treatment of acute infection. Although infections were major causes of death in almost all Pacific Island countries through the 1950s, the pattern changed in certain islands during the 1960s when non-communicable diseases and external causes emerged as the main causes of death (1989, p.636).

Indeed, the Cook Islands has low prevalence of infectious diseases, and had a successful anti-TB campaign during the 1950s and 1960s. This was partly contributed to the introduction of western medicine and was also a result of the Cook Islands receiving diagnostic equipment, treatment and specialists from New Zealand (Futter-Puati 2010). In fact today, the Freely Associated islands of Nuie, Tokelau and the Cook Islands have the lowest case numbers of TB annually across the Pacific (World Health Organisation 2009). These figures demonstrate that colonial relationships with New Zealand have produced some positive health outcomes.

More recently, as previously mentioned, regional attention is turning towards the interaction of both communicable and non-communicable diseases. Whilst some improvements in Pacific people’s lives both in New Zealand and the Pacific Islands exist, the future health of these people remains a major concern. In New Zealand, Pacific peoples are frequently cited as living in relative disadvantage in comparison to the New Zealand Pakeha population. Ministerial documents assert that Pacific peoples in New Zealand have poorer health status across a range of indicators “including child and youth health, and risk factors
leading to poor health and long term health conditions” (New Zealand Ministry of Health 2010, p.9). In the Pacific region, many countries are grappling with the challenge of high incidences of both infectious and non-communicable diseases (Taylor et al. 2005). In this thesis Cook Islanders health is positioned within both unequal development settings and a myriad of complex political relationships.

Research into disease in the Pacific mostly focuses upon working towards, monitoring and reporting health in accordance with global initiatives such as the Millennium Development Goals (MDGs) (Viney et al. 2011; World Health Organisation 2006, 2009). In 2009 the Cook Islands Government reported upon its “high levels of commitment to meeting our obligations and responsibilities to the worldwide concerns of our global family” (p.4).

Beyond the Cook Islands’ participation in the global community, the MDGs also provide the Cook Islands with benchmark health outcome indicators and a sophisticated way to both target health funding and channel health resources. Research on health and development in the Pacific is therefore largely designed and executed in a manner which reflects the current MDG development machine (Viney et al. 2011; World Health Organisation 2009 and 2012). This research takes an alternative view to nation centred responses to health and development by arguing that transnational behaviours and international relationships are a factor of health outcomes and there is need to understand the “differences and/or similarities in the health status of Pacific people in the islands compared with those born in New Zealand” (Tukuitonga and Finau 1997, p.60).

In New Zealand there are pockets of the population living in deprivation, and the health of these people is a serious issue (Salmond, Crampton and Atkinson 2007). Research by Cheer, Kearns and Murphy (2002); Howden-Chapman (1999); Kearns (1997); Littleton and Park (2009); Milne and Kearns (1999); and Mila-Schaff and Husdon (2009) recognise these health inequalities in New Zealand and connect the heterogeneous biological, social, economic and cultural dimensions at play. However, the public and population health documents produced by the Ministry of Health which target the Pacific peoples of New Zealand (New Zealand Ministry of Health 2010) are positioned within a ‘social determinants of health’ framework and frequently assume cultural, economic, and social homogeneity within the largest subsets of the Pacific population (Dunsford et al. 2011). It is important to note that these public reports demonstrate thinking beyond biomedical interpretations of
health by including social and cultural factors which influence health, however linkages between these social conditions and disease are not made. Furthermore, the diversity of health experiences and issues within the ‘Pacific’ population are somewhat diluted by the scale of this type of research.

**Framing ‘health’ research**

Before progressing onto a deeper understanding of how transnationalism may impact health, clarification of the term ‘health’ and what it means within this thesis needs to be established. The use of the term health often aligns with a basic definition that health is the absence of disease. Since 1948, the World Health Organisation has adopted a wider view of what health is to include a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organisation 1948). More recently, along with progress in evaluation and monitoring, ‘health’ is conceived as an indicator and a target of development projects and research. Within this framing, health becomes something to work towards, not something that is already achieved. It could also be argued, that within this view of health, that the body is perceived in a functional manner. To be healthy is to be functioning, whereas when you are unhealthy, something is not functioning as it should be within your body.

In a similar way, health research within Development Studies begins from the premise that everyone has the right to health and how ‘health’ is defined sets in motion interventions concerning the obstructions to health (The United Nations 1948). Nichter believes that “for impoverished people in developing countries, health is relative and prevention may largely be conceived in terms of preventing minor illnesses from becoming more serious ones” (2008, p.31). In this research I attempt to place more emphasis on how health is experienced by a Cook Islander and a key strand of investigation in subsequent chapters will be to clarify how health relates to Cook Islanders’ own experiences. The interrogation of the cultural associations of health was only possible by starting a discussion from a western reference point. Because of the close association with New Zealand and the provision of western medicine in the Cook Islands, I started conversations with Cook Islanders generally regarding ‘health’ as an absence of disease or debilitating condition.
Tracing the edges of the Cook Islands Transnational Social Field

As previously mentioned, the Free Association arrangement between New Zealand and the Cook Islands is a pivotal force behind the movement of Cook Islanders between the two countries. Historical and contemporary movement of Cook Islanders rests upon this relationship and with regards to health, dual New Zealand and Cook Islands citizenship allows Cook Islanders to leverage health systems in both places. At a rudimentary level, access to health services in New Zealand is dependant upon this political relationship. However, whilst this may appear to be a simple matter of crossing national borders to seek medical services, it is far more complex. Within the transnational social field, there are both a range of strategies and an extensive array of institutions involved in Cook Islanders’ search for health. From the outset of this research, the diversity of Cook Islanders’ mobility and the range of transnational activities and behaviours were believed to exert influence upon the health outcomes of Cook Islanders.

Cook Islanders are voyagers interested in life beyond their home island(s). In the past, movement was unrestricted around the Pacific region but, with the establishment of nation states, movement is now controlled and monitored between countries (Barcham et al. 2009). The contemporary movement between the Cook Islands and New Zealand has created dense networks of ties which connect people physically and emotionally across certain distances. Air travel facilitates these ties with increased frequency of movement to many other places, and new technologies have provided wider access to communications (Crocombe 2003). The density of ties connecting the Cook Islands to New Zealand, and vice versa, is not unique to the Pacific with similar patterns of mobility and international relationships existing globally (Portes 2003). The scale of population mobility in a globalised world and the “tempo driven by revolutions in communications and transport technology” (Daulaire 1999, p.1) is the new face of global movement of people, goods, ideas and capital. While nation states still exert influence, engagement with what has been coined a “transnational social field” is now common (Glick-Schiller, Basch and Blanc-Szanton 1995). Hannerz (1996), writing about globalisation generally and transnationalism as a result of globalisation, argues that globalisation “is not brand new, it can move back and forth, it comes in many kinds, it is segmented, and it is notoriously uneven; different worlds, different globalisations” (p.18). As Lee suggests ‘Peoples’ motivation for migration
are diverse but the desire to retain connection has long been a feature of Pacific Islanders' mobility” (2009, p.2). This framing of transnationalism has applicability in the Cook Islands context, given that the worlds where Cook Islanders live vary so considerably. Thus, it is worthwhile recognising from the outset that there is wide variance in the transnational behaviours and practices of Cook Islanders. With regards to health and transnationalism, whilst some of these transnational practices are tangibly within people’s control, some health-promoting and health-seeking practices are not. In an attempt to provide new applications and interpretations of transnationalism, this research incorporates Cook Islanders in both ‘home’ and ‘away’ contexts (Levitt and Jaworsky 2007; Tupai-Francis 2009). A dominant line of enquiry in this study is the transnational livelihoods of people within transnational social fields (Vertovec 2001; Friesen, Murphy and Kearns 2005).

Transnationalism challenges the notion that society is equated with the boundaries of a single nation state (Levitt and Glick-Schiller 2004; Levitt and Jaworsky 2007). The interrogation of the nation-state by transnationalism researchers has raised questions regarding basic assumptions of how people organise their lives. Under transnationalism, the state is a major influence on livelihoods, but this sits alongside people’s own influences and logic in determining their lives (Hannerz 1996). The ideas of where and what ‘home’ is, and what ‘host’ countries or ‘away’ places are, become less discernible as concepts of identity, citizenship, borders, place and economy are, for some people, fluid across space and through time (Vertovec 2004, p.979). In this way, transnationalism sees “the links between citizen and state as multiple, rather than disappearing” (Levitt and Jaworski 2007, p.134). This research is concerned with untangling the state policies around health and welfare that affect health and development outcomes for Cook Islanders.

**Transnational theory, Cook Islanders’ realities and possible syndemics**

The model of migration as a predominantly unidirectional flow of labour from a home country to a diaspora has been challenged by the emerging configuration represented by ‘transnationalism’ (Hoem 2009, p.191).

To early transnational theorists, population movement could not be perceived as an overly simplistic one-way movement of labour across static political borders and/or territories (Levitt and Jaworsky 2007). According to Bailey (2001), binary constructs, a heavy reliance
on positivist epistemologies and an inability to take the interaction of cultural and economic processes into account were identified as the major limitations for enquiry into migration. Tupai-Francis argues that fixing people in place, time and space ignores the more interesting and complex reality that the “ways, means, and reasons for movement are not so easily fixed” (2009, p.203-204). Communities today are no longer thought to be entirely “tangible, small, face to face entities, unproblematically situated in space”, instead they can now be “imagined” (Hannerz 1996, p.92). Cook Islanders’ imaginaries of what and where home is, encapsulates the often temporary and circular patterns of contemporary population mobility (Basch et al. 1994; Faist 2000; Glick-Schiller et al. 1995). These are brought to light in the case studies which feature in chapter five. The stories which feature in this thesis represent an interest in what Guarnizo (2003) refers to as ‘transnational living’. This framework, which was originally conceived as a way of understanding the different economics of transnational living, also has applicability in the context of health research. As Guarnizo argues:

Transnational living refers to a wide panoply of social, cultural, political and economic cross border relations that emerge, both wittingly and unwittingly, from migrants’ drive to maintain and reproduce their social milieu of origin from afar. The concept of transnational living allows us to detect myriad economic multiplier effects spawning from migrants’ transnational engagement, whose sought after and unforeseen compounding effects cut across multiple geographical scales, from the translocal to the transnational to the global (2003, p.667).

Transnationalism has become a productive framework for researching people’s livelihoods (Dunsford et al. 2011; Hondagnei-Sotelo and Avila 1997; Liki 2009). For the purpose of this research, key elements of the transnationalism discourse were distilled according to their applicability in the situation of combining both transnationalism and health research. The most significant elements identified include transnationalism from above and below (Portes et al. 1999; Bailey 2001, 2009; Ley and Waters 2004; Smith and Guarnizo 1998), transnational pathways (Chapman 1991; Hau’ofa 1993 and 1998; Lee 2009; Macpherson and Macpherson 2009; Nahkid 2009) and transnational social fields and simultaneity (Levitt and Jaworski 2007; Levitt and Glick-Schiller 2004; Glick-Schiller et al. 1995; Portes 2003; Portes et al. 1999; Landolt 2001).
The first key thread to discuss is the categorical distinction between transnationalism from above and transnationalism from below (Ley and Waters 2004; Portes et al. 1999, Portes et al. 2002; Smith and Guarnizo 1998). Typically, transnationalism from above includes global capital, media, and political institutions (Levitt and Jaworsky 2007). This research extends this view to also include the force of international health and aid agencies, migration policy, health systems and colonial relationships. Conversely, transnationalism from below proposes that people who move, retain connections physically, culturally and symbolically to places and other people. It focuses on the local and grass root experiences of people (Levitt and Jaworski 2007). A conceptual vertical movement of transnational experiences and behaviours between the transnationalism of “below” and “above” exists within this research. As Bailey argues, the transnational social field “destabilises the links between territory, assimilation and identity” (2001, p.420). People are thus engaged in transnational activities within a strategic process of transcending and transgressing boundaries (Ley and Waters 2004; Portes et al. 1999). The movement of people, transnational livelihoods and the destabilisation of the links between territory and identity is a common theme in Pacific transnationalism research. Researchers in this field emphasise the need for nuanced accounts of mobility and transnationalism (Alexeyeff 2004; 2008; 2009; Lee 2004, 2007, 2009; Nahkid 2009).

The notion of a transnational social field is the second key thread of the transnationalism literature used within this thesis. A transnational social field is a term which describes the space or arena where transnational behaviours, practices and activities transcend boundaries and borders (Levitt and Glick-Schiller 2004). It is also a space generating social activities stretching across geographical distance and time. Levitt and Jaworsky believe:

> These arenas are multi-layered and multi-sited, including not just home and host countries but other sites around the world that connect migrants to their conationalists and coregionalists (2007, p.131).

Within these social fields, people do not engage with the space in a homogeneous manner. Instead, the space is rich in networks of transnational processes with people frequently engaging in “multiple transnational processes at the same time” (Levitt and Glick-Schiller 2004, p.1028). These overlapping fields are designed and nurtured by the people performing transnational activities. It is within these transnational social fields that people
simultaneously remain active participants in countries, communities and families despite geographical distance. Burns-McGrath’s (2002) concept of Samoan transnationalism is useful when considering the case of Cook Islands transnationalism as well. To Burns-McGrath, transnationalism is:

... an imagined community, which is nothing like an imaginary community. The sense of connectedness is strong, the obligations are real. The boundaries of the multiple communities are flexible, allowing for membership in several simultaneously (2002, p.333)

These processes of simultaneity are not just concrete, easily identifiable activities such as sending money and gifts, voting in elections, church memberships, Facebook, Skype, phone calls, emails and travelling back and forth to cultural ceremonies. Processes of simultaneity also include:

... individual and family life courses and strategies, individuals’ sense of self and collective belonging, the ordering of personal and group memories, patterns of consumption, collective socio cultural practices, approaches to child rearing, and other modes of cultural reproduction (Vertovec 2004, p.977).

In addition, Barcham et al. (2009) believe that this way of life produces whole communities with multiple identities and allegiances. In reference to research conducted with Cook Islanders, Alexeyeff argues that:

... transnational relationships operate in multiple registers; they have economic, aesthetic, political and affective dimensions, and in order to grasp their significance one needs to explore these enmeshed components (2009, p.93).

The third thread of transnationalism literature is very descriptive and attempts to bring to life some of the idiosyncratic transnationalism practices. Using metaphors to describe the movement of people and their connections to places and people is a common feature within the Pacific transnationalism literature (Addo 2009; Alexeyeff 2009; Tupai-Francis 2009; Lilomaiava-Doktor 2009; Lee 2009). Lee asserts that this strand of the literature is shaped by an awkward relationship between state-imposed borders, cultural differences, and perceptions of social relatedness that transcend national boundedness (2009, p.15).

The most widely recognised scholar contributing to this discussion is Epeli Hau’ofa. Hau’ofa argues that the ocean surrounding the Pacific islands not only sustains the people and the islands, but is also a powerful connecting force between islands:
... the sea is our pathway to each other and to everyone else, the sea is our endless saga, the sea is our most powerful metaphor, the ocean is in us (1998, p.43).

In this well-known quote, the sea is depicted as an enduring path of social relationships. In this way, the ocean is engaged in a strategic manner, it is not a mere vast and open space without meaning or connections. Hau‘ofa also challenges western notions of the Pacific islands being isolated from each other and rest of world. Such a view endures today, as Wrighton and Overton states “The Pacific ocean is as large as all the other oceans in the world put together yet the land masses and populations in it are tiny” (2011, p.246). This depiction describes Oceania in a particular way, and illustrates adherence to the pervasive notions of vastness and vulnerability.

Beyond the metaphor of the ocean, Pacific literature on transnationalism recognises the transnational pathways opened up by colonial ties (Alexeyeff 2009; Lee 2009), pathways of ancestry and kinship ties (Evans et al. 2009; Hau‘ofa 1993, 1994; Lilomaiva-Doktor 2009; Macpherson and Macpherson 2009) and pathways facilitated by remittances (Addo 2009; Bertram 2006; Borovnik 2009; Lee 2009; Marsters et al. 2006; Park et al. 2011; Underhill 1989). The point of difference in this body of literature is that that these pathways are investigated from the position of what it means for those who have designed them and those who navigate them. Borovnik believes “it is not the boundaries of the nation state but the processes, symbols and meanings within it that are the defining terms in which transnational processes are played out” (2009, p.153). It could be argued that this body of literature looks deeply at the patterns and meanings of transnationalism. To uncover the patterns and meanings of transnationalism in the Pacific, ethnographic forms of research and analysis are frequently used to describe the connections these people have with people and places and the triumphs and obstacles they faced (Liki 2009; Pollock 2009).

It should be noted that the patterns and meanings of transnational pathways in the Pacific are commonly applied to culturally affirming and positive research projects. For example, Pollock (2009) views food and ‘foodscapes’ as reinforcing Pacific people’s links to each other and the wider world while Addo (2009) explores the ceremonial gifting of cloth and cash within the Tongan diaspora. Studies such as these provide vibrant illustrations of life as a Pacific person engaging in transnational behaviours, which is vital considering the
alternative views of Pacific peoples however, other researchers consider both positive and negative elements of transnationalism. For example, Horan in her research of Tivaevae and Cook Islands ceremonial gifting acknowledges that “The reality of living in a big city like Auckland is not like living in the village in the islands where kin were neighbours” (p.24) and as such Cook Islanders have created “subaltern strategies to get by and prosper in New Zealand” (2012, p.3). Alexeyeff in a similar manner comments upon the fragility of transnational Cook Islands communities:

... [in] that the process of maintaining and reconstituting transnational communities is also accompanied by loss and dislocation. While there is much to celebrate about the tenacious way that Islanders preserve their community and familial connections across geographical distance, to complete the picture of these transnational relationships we must acknowledge that globalisation also makes these relationships potentially fragile (2009, p.99).

To extend the literature further, academics internationally are making a call for research which speaks to the consequences of transnationalism which are normally hidden from view. As Levitt and Jaworsky state:

Though growing more nuanced in their approach, transnational migration studies still tend to be more positive than negative. Future work needs to take a hard look at what the determinants of positive and negative outcomes are and to explore the relationship between them (2007, p.144-145).

One of the negative manifestations between globalisation and health in the Pacific can be seen in the complex and ever changing trade negotiations in relation to food policy. Food purchasing by local people in Pacific countries is heavily influenced by trade agreements which have seen the reduction of tariffs on imported (and often calorie dense) food stuffs (Kiloe 2009). Evans, Sinclair, Fusimaholi and Liava’a conducted research in Tonga on the relationship between food purchasing behaviours and nutritional knowledge and established that:

Although educational programmes have increased awareness about healthy diets and nutritional foods, people in the Pacific nonetheless choose to consume less healthy foods because of cost and availability (i.e. they make economically rational, but nutritionally detrimental decisions to consume certain foods). Thus, poor diet is not simply a health or health education issue, it is also economic (2001, p.856).
The relationship between food, trade and the Cook Islands transnational social field is another contextual layer to the complex environment in which this research has taken place.

Overall, this chapter has shown that Cook Islanders in New Zealand and the Cook Islands are part of a dynamic transnational social field. Both historical and contemporary relationships between New Zealand and the Cook Islands continue to shape the transnational livelihoods of Cook Islanders in multiple places. The socio-political, cultural and economic characteristics of these places are highlighted in the proceeding chapters via the application of a syndemic framework. In these chapters, an understanding of transnational living is built upon with the use of primary and secondary research material on the topic of TB and diabetes.
CHAPTER THREE
Background to syndemic theory, research and applications

Movement within the Cook Islands’ transnational social fields is diverse and complex. To narrow the route of enquiry into the relationship between transnationalism and the health of Cook Islanders, I used syndemic theory as the analytical frame. There are fundamental elements of both transnationalism and syndemic theory that allow these two theories to work together. Transnationalism theory and syndemic theory both stress the importance of connections, particularly the connection between livelihoods and socio-political forces. Both of these approaches also allow for creative research design and mixed methodologies. Within the literature it is clear that researchers in these fields are concerned with the issues faced by certain populations (Alexeyeff 2008; Singer and Clair 2003). This chapter progresses towards a route of enquiry designed to convey the lived experiences of Cook Islanders living with TB and diabetes using a syndemic framework.

Singer et al. writes with clarity on the wider connections and interactions that contribute and exacerbate experiences of disease:

... it has become increasingly clear that diseases do not necessarily exist in isolation from other diseases and conditions, that disease interactions are of considerable importance to disease course and consequence, and that the social conditions of disease sufferers are critical to understanding health impacts at the individual and population levels. Rather than existing as discrete conditions, multiple life-threatening diseases often are concentrated in particular populations (Singer et al. 2006, p.2011).

The above quote urges researchers to consider the forces which impact upon the concentration of diseases in certain populations. To accept that there are disease interactions spurs an interest in the content of the connections between one or more interactions that contribute to an increase in disease burden (Candib 2007; Egan et al. 2011; Everett 2009; Freudenberg et al. 2006; Herring and Sattenspiel 2007; Kurtz 2008; Singer 1996, 2009; Singer et al. 2011 and Singer and Clair 2003; Stall et al. 2003). For example, Freudenberg et al. argue that epidemics of TB, HIV infection and homicide in New York City share underlying social determinants which synergistically create an excess of disease
burden upon the population. The rise of epidemics from the late 1970s through to the mid 1990 is positioned by these authors during a period of fiscal crisis which led to:

Cuts in services, the dismantling of health, public safety, and social service infrastructures; and the deterioration of living conditions for vulnerable populations contributed to the amplification of these health conditions over two decades (2006, p.425).

Writing about the same period of time in New York, Wallace and Wallace argue that:

The tuberculosis and AIDS epidemics within the city demonstrated the lack of respect for jurisdictional boundaries, class, ethnicity, sex, age, and sexual orientation held by contagious processes. AIDS jumped from largely white, middle class, gay communities concentrated in Greenwich Village and the West Side, to intravenous drug users and minority homosexuals. Tuberculosis fanned out from primary and secondary epicentres across whole boroughs and claimed white middle class victims, even a few wealthy ones. Even white children, by 1990, were drawn into the contagious-epidemic process (1998, xviii).

The authors in the above quotes place diseases within mechanistic interacting processes. This emphasis upon the consequences of complex synergies within population clusters sets syndemic theory apart from other public health tools such as the “social determinants of health” model. Syndemic frameworks differ in that they emphasise the interaction of the combined factors, as opposed to the correlation of series of distinct relationships. While the social determinants of health model critically unpacks the biological, structural, social and environment conditions that contribute to an uneven distribution of disease (World Health Organisation 2008), each factor within this model is assessed for its influence on a pathway towards ill health. Syndemic theory has proved useful for researchers and public health specialists who believe that public health should be reconceived under a model which promotes collaborative efforts to offer appropriate palliative care and more effective preventative strategies for those most vulnerable to disease (Candib 2007; Edberg et al. 2011; Gassman et al. 2012; Milstein 2004; Raviglione and Uplekar 2007; Ventura and Mehra 2004). One of the remaining challenges is to transfer the application of syndemic frameworks into health priorities programmes which can produce multiple positive outcomes in more than one area (Singer et al. 2011).

A common feature in the syndemic literature is that social inequality, fiscal crises and cuts in social services not only lead to the clustering of disease in certain populations, but also
exacerbate their experience of disease burden (Freudenberg et al. 2006; Jones et al. 2006; Singer 1994; Singer and Clair 2003). The application of this syndemic framework prioritises how living in overcrowded housing situations where inadequate nutrition, social isolation, stigma and unemployment manifest and affect a person’s experience of disease. For the Cook Islanders within this research, overcrowding, inadequate nutrition, stigma and transnationalism interactions were found to intensify the TB and diabetes syndemic.

Singer remains the seminal author in this field; however, many other researchers have adopted this concept as a way to extend their analysis of health and social problems (Antunes 2001; Albalek et al. 2007; Candib 2007; Edberg et al. 2011; Freudenberg et al. 2006; Kurtz 2008; Kwan and Ernst 2011; Mendenhall 2012; Singer and Clair 2003; Singer et al. 2006; Stall et al. 2003). The term ‘syndemic’ was first used to explain the “synergistic or intertwined and mutually enhancing health and social problems facing the urban poor” (Singer 1994, p.931). Since this time, syndemic theory has evolved from the source discipline of critical medical anthropology to what Singer claims is a “new way of thinking about the causes of sickness” (Singer 2009, p.1). The focus for Singer’s early work was on HIV/AIDS within the US during a time of fiscal, political and social crises (Singer 1994, 1996). This work reconceptualised AIDS within particular economic and historic processes and demonstrated that health research need not be constrained by traditional thinking of how we view disease and undertake health research. Rather than dealing with HIV/AIDS within a social, economic and historic vacuum, Singer placed HIV/AIDS alongside other afflictions framed within a significant context (Milstein 2004). As the theory gained popularity the application of the theory moved beyond connections with HIV/AIDS to include a range of diseases, social problems and communities. Over the course of 15 years the expressions of syndemics have diversified according to particular populations, biological, and social contexts. It is this diversity and the creativity of syndemic frameworks within health research that speaks not only to my own research intuitions, but also to the complexity of research with transnational Cook Islanders. The manifestation of particular health issues occurring in ‘biosocial environments’ dovetails with this thesis’s guiding premise that transnationalism has implications for health. This environment, or the social transnational field, is demonstrated within this thesis to have influenced the social conditions which have contributed to the TB and diabetes syndemic in the Cook Islands population.
To further understand the application of a syndemic framework Singer explains:

To the degree that it encourages a focus not just on disease interactions but on the fundamental importance of the social conditions that foster disease clustering and interfaces, syndemic theory also represents a paradigm shift in the understanding of what disease is and how it is manifested in a complex biosocial feedback environment (2009, p.16).

In other areas of health research and policy, syndemic theory has gained popularity as an effective policy tool. The Centre for Disease Control (CDC) in the USA is the main champion of the application of syndemic frameworks. The CDC provides operational resources for researchers, institutions and governments seeking a more holistic model for health research. At this level, syndemic research and possible applications have been closely defined as:

- Connections between health-related problems
- A framework for understanding how they interact
- Examining the conditions which create and sustain overall community health
- This orientation leads to the questions:
  - Who is sick?
  - Why those people?
  - Why those diseases?
  - What can be done to create (or restore) conditions for optimal health?
  - Under what circumstances do interventions in health status and health equity occur?

(Syndemics Prevention Network, Centre for Disease Control 2002)

Ten years later a set of useful critical understandings was designed by Ostrach and Singer (2012) to assist future syndemics research. These critical understandings develop the different elements of syndemic research and provide a useful tool for framing a syndemic research project. To undertake syndemic research you start from the understanding that physically and emotionally adverse social conditions weaken the body’s capacity to resist and fight disease. From this position you are able to explore how social conditions facilitate
disease onset and transmission and promote the concentration of disease in marginalised populations. A statement can then be made about the likelihood that specific diseases will interact in ways that exacerbate the disease burden of a population (Ostrach and Singer 2012).

**Implementation of syndemic research**

Collaboration across the academy, government, non-government and global health institutions is another defining element of a syndemic orientation. As the understandings provided by Ostrach and Singer (2012) convey, multiple frameworks of understanding must be brought together to analyse the contributing conditions which connect the health issues. This fundamental intersection expands co-morbidities thinking by prioritising the health and society interactions that support clustering of multiple diseases in vulnerable populations (Singer et al. 2011). This intentionally makes a wider call within the world of public health for collaboration across disciplines, disease and organisational boundaries (Raviglione and Uplekar 2007).

In this thesis, the use of mixed methodologies across multiple political and bio-medical boundaries disrupts service boundaries in both New Zealand and in the Cook Islands. The dialogue initiated as part of the wider “Transnational Health in the Pacific through the Lens of TB” project stretched across geographic and institutional boundaries and opened up further discussion on syndemic diseases across sectors. This dialogue is a critical by-product of the syndemic orientation in that it allows for people across a range of sectors to step out of their silos and develop more holistic thinking about health issues (Singer 2009). This research has promoted the TB and diabetes syndemic to people, families, epidemiologists, microbiologists, government ministers, non-government organisation employees, medical clinicians, policy analysts and social scientists. In many cases employees in the health sectors were aware of this connection anecdotally and participants’ stories of TB and diabetes frequently included personal experiences of both of these diseases. Syndemic discussions thus provided people with a new way to think about the patterns and meanings of TB and diabetes. It also raised questions about the threat this syndemic poses for Cook Islanders.
Recently the Secretariat of the Pacific Community (SPC) launched an operational research project on the ‘double burden’ of TB and diabetes in the Pacific region. In collaboration with the International Union against Tuberculosis and Lung Disease, CDC, WHO, The University of Auckland and Fiji National University this project aims to “produce two-three country led operational research projects focusing on TB and diabetes, which will provide local knowledge and evidence to shape TB and diabetes activities and direct health policies in the Pacific region” (World Diabetes Foundation 2013 ). This project has not explicitly stated the use of a syndemic framework, however, it does demonstrate collaboration across the Pacific region and an awareness of the interaction between TB and diabetes.

Importantly, this project recognises that conventional approaches that attempt to alleviate the burden of these diseases within developing Pacific nations need to change in response to new understandings of disease pathways. The outcome of this project is anticipated to redesign the frameworks of diagnosis and treatment of this “double burden”.

All research within development strives for positive intervention (Sumner 2007) and in this way a syndemic framework’s ability to prioritise key interventions that will produce multiple outcomes (Nichter 2008) is suitable in the context of development. Furthermore, development research and syndemics also share an interest in the interrelated dimensions of health and profiling the experiences of people living in unequal circumstances (Hudson 2009). Within a syndemic framework, tools such as The Millennium Development Goals7 (MDGs) are recognised for their ability provide consistent language with tangible target activities and outcomes for those in the development and policy sector however, the rigidity of the measures and the appropriateness of cross country comparisons are brought into question. For example, a review of the syndemic literature led me to question the inability of the MDG framework to deal with mobile people and the interrelationships between communicable and non-communicable disease. Issues of scale, remoteness and socio-political and cultural elements is also problematic. This demonstrates that when used within development research syndemic theory can offer a contemporary approach to critically engage with the development environment.

7 In all but Papua New Guinea, Pacific countries are on target for meeting the TB related MDGs (Viney et al. 2011).
The main historical process that has complicated and the increased disease burden for Cook Islanders is, within this research, considered as colonisation. In the Cook Islands setting, colonisation is overt in the currency, governance structure, predominant spoken language and educational systems. Free Association may be considered an economically pragmatic health provision solution for both nations but in terms of health and health care, this thesis will demonstrate that Cook Islanders’ citizenship and corresponding health service access is differentially and at times unequally experienced. Outside the scope of this thesis, it needs to be flagged that certain trade relationships between New Zealand and the Pacific have been health demoting, particular with regards to the relationship between food, nutrition, obesity, diabetes and trade agreements. In summary, Legge, Gleeson, Snowdon and Thow states that:

... removing tariffs makes imported high fat foods like mutton flaps and turkey tails cheaper. They can become cheaper than local fish or locally produced lower fat meats, thus encouraging consumption (2013, p.12).

This arises as one of the many potentially detrimental consequences of trade agreements and the removal of trade tariffs in Pacific Island Countries (PICs). Another issue relating the complexities of trade agreements in the Pacific region in relation to positive health outcomes is concern that entering into agreements such as Pacer-Plus\(^8\) would contribute to:

Increasing the price of medicines by making pharmaceutical patents easier to gain and making it more difficult for development countries to import or manufacture generic, lower cost equivalents (Legge et al. 2013 p.12)

These two examples of Pacific nations having less ability to negotiate access to high quality food and sustainable health promoting resources provides another dimension to the complexity of the health and transnationalism in the Cook Islands. The on-going relationship between New Zealand and the Cook Islands takes multiple forms through aid, migration, currency, education and trade relationships. The trade relationships have been mentioned in this section to signify the different patterns of health that colonial

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\(^8\) PACER Plus is a proposed trade, development and economic cooperation agreement currently negotiated by the thirteen Pacific Forum Island Countries (FICs) with Australia and New Zealand.
relationships can generate. This aspect of transnationalism and health is expanded upon in chapter eight.

Population centred research

In effect, it is the person or group of people who are the centre of concern, not the disease itself, unlike in many clinical contexts today where TB is treated (Roberts 2002, p.30).

Singer (2009) argues that particular disease(s) and/or health problems disproportionately affect residual pockets of the population. Populations may be linked through a gender and behavioural commonality such as Men who have Sex with Men (MSM) (Egan et al. 2011) or people who share a cultural identity (Candib 2007). In syndemic research the term ‘population’ is also used to define a group of people within a particular place whether it be a city or country. This research, however, follows Farmer’s (2000) methods to connect the research findings from diverse populations in multiple locations and across nation states. Farmer carried out ethnographic TB research in rural Haiti, urban Peru and in inner-cities of the United States. His research argues that:

... we must explore not only the life experiences of those sick with tuberculosis, but also the larger social contexts in which they become infected, fall ill, and meet with a series of therapeutically misadventures leading to complications, on-going transmission to others and often enough, death (Farmer 2000, p.183).

The defining features of the population within this study are the experiences and perspectives of people with Cook Islands heritage who have both or either TB and diabetes. The study includes both genders and evaluates the disease experiences of both men and women living with TB and diabetes. In doing so it provides opportunities to position the experiences of diabetes (Farmer 2000) in both genders and Gestational Diabetes Mellitus (GDM) in women (Cundy 2008) and makes a wider call for considering the role of gender within a syndemic framework. The consideration of gender within this research includes both female and male experiences of diseases beyond the biological. The intention is to raise not just the biomedical implications of gender but also the social context of the differential experiences of TB and diabetes between men and women. There is also a temporal dimension to the TB and diabetes syndemic. For this study, it is necessary to consider the combination of the insidious onset of diabetes and frequent delays in diagnosis and differences between latent TB and TB disease (TBD) for Cook Islanders. The
historical epidemic of TB in the Cook Islands is likely to have produced high levels of latent TB in the population (Futter-Puati 2010), which can be reactivated if the person also develops a lowered immune response as a result of diabetes (Restrepo et al. 2006). It is important to keep in mind the generational dimension to Latent TB infections in the case of Cook Islanders. In the Cook Islands, new case numbers of TB were over 100 in 1965 and decreased significantly to 11 cases in 1975 (Futter-Puati 2010). Therefore, whilst the likelihood of Latent TB infection decreases for those born after 1975, the older cohorts of the Cook Islands population are at risk to reactivation of Latent TB. As Futter-Puati (2010) argues, we can never become complacent where TB is concerned (Futter-Puati 2010).

The potential threat of the diabetes and TB co-morbidity

Restrepo et al. 2006 and Wang et al. 2009 illustrate that the growing diabetes epidemic is aggravating the risk of, and accelerating the rate of TB globally. In simple terms, TB triggers diabetes and when diabetes is already present, it acts as a risk factor for the development of TB (Alisjahbana et al. 2006; Perez et al. 2006). Some researchers anticipate that the risk of TB for patients with diabetes may supersede the risks associated for those with HIV/AIDS (Restrepo et al. 2006). With increasing numbers of people with diabetes, populations are becoming more vulnerable to TB (Perez et al. 2006) and when TB and diabetes interact inside a person’s body, research has proven that people present particular morbidities, further vulnerabilities, and mortalities. Aside from recent research being undertaken in the Pacific, evidence of TB and diabetes co-morbidity has been gathered through studies in the USA and Mexico (Restrepo et al. 2006), India (Stevenson et al. 2007) and Indonesia (Alisjahbana et al. 2006) with the overall hypothesis being that the association between diabetes and TB is likely to be related to a weakening of immune responses (Restrepo et al. 2006). Recent research in the Western Pacific\(^9\) estimates that 42% of all TB cases may be attributable to diabetes (Viney et al. 2011).

\(^{9}\) It is important to note that the Western Pacific covers a wide range of countries from China in the north and west, New Zealand in the south and French Polynesia in the east.
A summary of particular morbidities and mortalities associated with the TB and diabetes syndemic follows:

- The risk of TB in persons with DM is expected to be around 1.5–8 times higher than those without DM (Stevenson et al. 2007).
- TB-DM cases have also been found to be more contagious. This is influenced by a delay in diagnosis because a person with TB-DM may not fit the typical profile of person at risk of TB (Restrepo 2006).
- People with TB-DM are also more than twice as likely to remain sputum culture positive at the end of treatment (Stevenson et al. 2007).
- The TB-DM co-morbidity results in higher frequency of cavitation (Restrepo et al. 2006).
- The TB-DM co-morbidity results in the higher frequency of mortality (Alsijahbana 2006; Restrepo 2006).
- The higher frequency of multi drug resistance (Restrepo 2006).

The research relating to the connection of TB and diabetes (Alsijahbana 2006; Restrepo 2006; Stevenson et al. 2007) is not explicitly syndemic because it focuses upon the TB and diabetes co-morbidity; however, this work has been influential in the framing of subsequent syndemic studies. The potential risk of the co-existence of these diseases was examined by these authors from a biomedical and epidemiological position. A syndemic approach would use these understandings and also identify the synergistic interactions of socio economic, cultural and political dimensions.

This thesis argues that a syndemic framework provides a vehicle to systematically consider how the health priorities of ministries, local governments, NGOs, communities and international relationships affect TB and diabetes among Pacific peoples in the New Zealand context (Littleton and Park 2009). In 2003 the rate of Tuberculosis Disease (TBD) was six times higher in deprived areas when compared with the least deprived neighbourhoods in Auckland (Thornley and Wall 2004) and although the rates of TB in the general population are low, Pacific peoples have not experienced a decline in rates of TB (Das et al. 2006). In 2006 there were significantly high rates of TB among Pacific elderly
(c185-190/100 000) as well as evidence of significant active transmission of TB from adults to children (Das et al. 2006). In one cluster a total of 24 children from one small Pacific community were infected with TB between 2002 and 2003 (Voss et al. 2006). A multidisciplinary project involving the political ecology of TB with Maori, Pakeha, Pacific, Chinese, Indian and Somalian communities revealed that people’s experiences of TB were influenced by a range of socio-cultural factors (Anderson 2007; Lawrence 2007; Littleton and Park 2009; Ng-Shiu 2006). This work makes a case for looking more specifically at the uneven distribution of disease in Auckland.

Littleton and Park (2009) saw possible connections between TB, diabetes and deprivation for Pacific peoples. These authors positioned the high incidence of diabetes and associated health problems in the New Zealand Pacific peoples’ population as a possible and very serious interaction with the already established link between TB and deprivation. The concern for these authors is that Pacific peoples in New Zealand have disproportionately high rates of both TB and diabetes and TB is actively transmitted. These higher rates of TB are partly historical (Sexton, Perea and Pandey 2008); however, the persistence of the disease may be amplified by high rates of diabetes particularly among older people (Littleton and Park 2009). The TB the TB-diabetes co-morbidity produces a more contagious form of TB, and because TB in diabetes patients is also harder to diagnose, it poses a serious threat to Pacific peoples in New Zealand. Therefore this co-morbidity does not only significantly increase the burden of disease for people, it also makes TB even more difficult to control. In the Cook Islands, TB has been well controlled with only one to two cases reported per year (Viney et al. 2011). However, the history of TB in the Cook Islands and the high rates of diabetes in the population pose a risk of future TB epidemics.

On the US-Mexico border, Perez et al. discovered that “patients with diabetes had more than twice the risk of TB compared with patients without diabetes and non-border countries patients with diabetes had >1.5 times the risk of TB as a patient without diabetes” (2006, p.608). People with diabetes who are exposed to TB have a “greater risk of TB than those with only exposure” (ibid). The research of Littleton and Park (2009) and Perez et al. (2006) indicates that growth in the number of people with diabetes is making populations more vulnerable to TB infections.
The impact of harmful social conditions

As the case of TB suggests, diseases do not exist in a social vacuum or solely within the bodies of those they inflict, thus their transmission and impact is never merely a biological problem (Singer and Clair 2003, p.428).

TB and diabetes are both referred to as diseases of poverty (Rock 2003; Kwan and Ernst 2011; Farmer 2000). In a quantifiable sense, poverty expressed as Gross Domestic Product (GDP) can be directly related and modelled against the incidence of TB (Kwan and Ernst 2011). Numerical representations such as this are useful for framing research, however, in this thesis, qualitative accounts in the form of narratives and observations are used to understand Cook Islanders’ experiences of poverty and corresponding health demoting conditions. For researchers using qualitative methods evidence of poverty can be found within the stories of hunger, bad harvests, leaky roofs and dirt floors (Farmer 2000, 2007). Littleton and Park (2009) believe that the underlying socio-economic and political position of Pacific peoples in New Zealand with diabetes is a key contributor to the disproportionate impact of associated health conditions. For example Scragg et al. 1991 found the prevalence of diabetes mellitus to be higher among those on lower incomes and there are many Pacific people in this category. A few years later, Simmons (1996) argued that the situation of Maori and Pacific with diabetes is of grave concern, given that these populations experience an earlier age of diagnosis, poor glucose control and more end-stage renal failure and blindness.

Globally, diabetes is now recognised as a disease of the poor and an important development issue as more than 80% of all deaths related to diabetes (including Types 1 and 2) occur in low and middle income countries (World Health Organisation 2012). A key part of this research is to unpack the multiple meanings of the term poverty in an attempt to tease out which particular harmful social conditions are at play in the Cook Islands population. A collection of existing literature on the topic of harmful social conditions and health is outlined below to suggest that particular health and development issues exist for the Cook Islands population.
Nutritional change, food security and the transnational social field

Malnutrition as a condition of social inequality contributes to the syndemic enhancement of disease (Singer and Clair 2003). On a biological level, malnutrition lowers the immune system and increases the risk of TB reactivation and the active transmission of TBD. For people with TB, good nutrition can also be attributed to a more rapid clearance of bacteria and “radiographic changes in addition to greater weight gain” (van Lettow 2003, p.8). When no drug treatment was available during the TB epidemic in the Cook Islands in the twentieth century, positive results were found to occur when patients were provided with good food and access to fresh air and rest in a well-ventilated room (Futter-Puati 2010). Nutrition and the relationship this has with immune responses is a crucial player in increasing and limiting both TB and diabetes. In the Cook Islands and among Cook Islanders in New Zealand, it was discovered that healthy food was expensive and therefore access to nutritious food must be viewed as part of wider economic and political forces. For example, as previously mentioned, trade agreements and reduced tariffs have produced a scenario where imported, low nutritional value food is favoured because local food production has declined as a result of price differentials and the outward migration of people to work on plantations. Food within a syndemic framework therefore becomes a central factor of biological responses and lowered immune systems, international political agreements, cultural preferences, ceremonies, and economic decision making. The important distinction here is that food behaviours are not viewed as solely an individual’s responsibility but as part of wider, complex socio-political and economic factors.

The incidence of diabetes is on the rise.\(^\text{10}\) Contemporary diabetes reflects the social gradient and the complications of this condition unequally burden people in less developed countries (Rock 2003; Hu 2011). While excessive calories are a major driving force of this disease, more emphasis is now being placed on ‘diet quality’ (Hu 2011). The manifestation of diabetes continues to occur predominantly in adulthood; however, this disease is occurring more frequently in adolescents and children. This signals that diabetes is the result of poor nutrition over a life course and research now highlights that poor nutrition in utero and early life, combined with over nutrition later in life is playing a key role in this

\(^{10}\) According to the WHO 347 million people have diabetes worldwide. The WHO also projects that diabetes deaths will increase by two thirds between 2008 and 2030.
epidemic (Cundy 2008; Hu 2011). Urbanisation, globalisation and economic development are instrumental characteristics of the changing face of diabetes (World Health Organisation 2012).

In the total New Zealand population, there is an increase in the amount of young people with diabetes and GDM. A cycle is emerging where the increasing risk of diabetes or undiagnosed diabetes in younger populations is leading to higher incidences of GDM acquired during pregnancy. Complications include congenital defects in the foetus, hypertension in the mother and an increased risk of still birth (Cundy 2008). Vitamin D deficiency, caused by both environmental factors and nutrition, is implicated in both TB and diabetes and is yet another connector of TB and diabetes. A survey in New Zealand revealed that both ethnicity and season were other major associations that disproportionately affect Maori and Pacific peoples (Scragg et al. 1995). Several years later, Scragg and Bartley (2007) reiterated that in New Zealand, Pacific people’s mean Vitamin D levels are still lower than that of the total population and less than what is necessary for optimum health.

Within this study, the syndemic framework incorporates the pervasive force of structural and environmental conditions on people’s access to nutrition. For example, Herring and Sattenspiel (2007) argue that episodes of malnutrition are associated with chronic stress, which further increases a person’s susceptibility to diseases. This “nutritional stress” permeates whole families as they struggle to provide adequate nutrition to each of its members (Herring and Sattenspiel 2007, p.191). Nutrition and its relationship with socio-economic position and increased disease susceptibility is a key axis on which both communicable and non-communicable diseases rest. The biological relationship between the body and food form only one part of this relationship.

**The socio-biological and environmental interactions of TB and housing**

The connection between TB and household crowding is the most cited socio-environmental and biological interaction (Baker et al. 2000; Dunsford et al. 2011; Milne and Kearns 1999; Prior 1989; Tukuitonga and Finau 1997; Singer et al. 2006). Overcrowding is another of the

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11 GDM is a result of impaired glucose intolerance and has complications for both the foetus and the mother (Asian-Pacific Resource and Research Centre for Women (ARROW) and World Diabetes Foundation 2012).
key socio-economic problems that increases a variety of different disease susceptibilities (Singer 1994). Families with lower median incomes and more people living in crowded conditions as a way to minimise cost are more likely to house TB cases (Wanyeki 2006). Families thus experience the effects of higher levels of disease dissemination (Cheer et al. 2002; Crump, Murdoch and Baker 2001; Milne and Kearns 1999). Cheer et al. argues that residing in overcrowded conditions in New Zealand reveals that “discounted” health decisions are made as part of prioritising limited resources (2002). In an overseas context, Farmer argues that overcrowding is just one example of “how social inequalities come to have a pathogenic effect” (2000, p.186).

Specifically, with regards to TB in the in New Zealand context, Baker et al. found that “household crowding makes an independent contribution to TB transmission” (2008, p.718). This research asserts that while household crowding occurs because of a range of socio-economic and cultural reasons, it is only a risk factor when there is a source case of infectious TB (Baker et al. 2008). For this reason, the authors advocate that local and relatively recent transmission and subsequent development of the disease is more likely to be attributed to household crowding than reactivation of previous TB infections (Baker et al. 2008, p.717). This also directs our attention to the additive interplay (Stall et al. 2003) of health conditions in the TB and diabetes syndemic.

It is important to note that research on the connection between the living conditions of people with either or both diabetes and TB is complicated by the insidious onset of diabetes and the variable period of latency of TB. Undoubtedly, environmental and social conditions experienced over the life course of a person will reflect the health and wellbeing of that person. For Cook Islanders, their experiences of crowded living conditions may be sporadic or constant depending upon the travel and accommodation needs of individuals and extended families. This produces the complex challenge of distilling these dimensions into a tangible set of interactions within the TB and diabetes syndemic.

**Tobacco smoking**

Tobacco smoking not only causes illness but also amplifies existing illness and causes disease relapse. In the case of diabetes, tobacco use results in serious complications and a much higher risk of mortality; and in the case of TB, tobacco use is related to a significantly
higher risk of relapse. In terms of health statistics, the Census in 2006 recorded 38% of the population as smokers with a further 13% stating that they used to smoke. In 2006 the national Census of the Cook Islands recorded 29% of the population aged 15 and over as daily smokers (Cook Islands Government 2006).

Silverstein alerts us to the wider influences involved in the interaction of tobacco smoking and disease. For example:

- those who smoked were most likely to be inactive and had poorer control of their diabetes, factors that further increased their risk of early cardiovascular disease. Those who were most likely to partake in these behaviours were of lower socio economic class (2011, p.594).

Tobacco smoking is a harmful social behaviour and has been proven to increase associated health conditions in both TB and diabetes patients. Within this study, considering tobacco smoking as part of the syndemic demonstrates the importance of causality as tobacco smoking is one mechanism which makes other health conditions worse. Furthermore the “deleterious health effects of cigarette smoking” warranted inclusion because of the threat this behaviour poses to both TB and diabetes patients (Storholm et al. 2011, p.664). In addition to the additive effect of tobacco smoking to existing disease Godoy conducted research in Spain among TB cases and contact cases which highlighted that latent TB was more prevalent among contacts of smoking index cases (2013). Not only does this signal that TB and tobacco smoking increases contagion but also the possibility that “a reduction in smoking could lower the risk of infection substantially” (2013, p.771).

**Stigma, migration and disease**

This research highlights the role of stigma upon Cook Islanders’ experiences of society, health and self. I argue that syndemic frameworks which have largely focused on the interplay of stigma and HIV/AIDS (Singer et al. 2006 and Stall et al. 2003) also provide the opportunity to work through how this phenomena interacts with TB and diabetes within a transnational population. In this syndemic framework two particular types of stigma are included. In particular, this research deals with the issue of self-esteem affected by self-stigmatisation and an awareness of the negative impression others have of them (Camp et al. 2002, p.825) and experiences of isolation, shame and othering (Nichter 2008). The internalised and externalised dimensions of stigma are included within the syndemic
framework as a result of complex relationships between stigma, and identity in the face of disease diagnosis and migration history.

For example, Sexton et al. (2008) via the use of molecular typing argues that there is evidence of active transmission of TB and between 2003 and 2008 the average notification rate of TBD for Pacific peoples was around three times higher than the average rate. Littleton and Park in their review of TB and health literature for Pacific people in New Zealand stated that:

> While high rates of TBD among Pacific elders today is partly a reflection of the historical pattern of tuberculosis in the Pacific and also among those who migrated to New Zealand in the 1960s and 1970s, active transmission to children is a marker of current living conditions and life situations. Given the high rates of diabetes among Pacific populations and the high rates of transmission of LTBI\(^{12}\) and conversion to TBD in certain circumstances, we hypothesise that TB and diabetes are part of a syndemic affecting particular Pacific groups (2009, p.1677).

Statements such as the one above work towards demystifying the relationship between disease, migration and stigma. Advances in DNA fingerprinting\(^{13}\) now allow clinicians to understand if the TBD is a new infection or a reactivation. In New Zealand, TB among Somalian refugees was far more likely to be caused by reactivation of latent TB (Lawrence 2007). This reactivation was attributed to “multiple and overlapping layers of disadvantage, factors which have been linked to the prevalence of TB” (Lawrence 2007, p.211). Active TBD may also manifest because of the social ties and living patterns of people in a new community which may make them more susceptible to infection (Egan et al. 2011; Littleton et al. 2008; Oest, Chenhall, Hood and Kelly 2005).

The literature in this section suggests that research must work towards dispelling the notion that migrants ‘import’ diseases. The generation of stigma towards migrants with or without disease is explained by Nichter as:

> the course of identifying groups at risk can foster a process of blaming and “othering” that stigmatises groups and reinforces pre-existing prejudices and group animosities (2008, p.45).

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\(^{12}\) Latent Tuberculosis Infection

\(^{13}\) This technology is not available in the Pacific Islands
Stigma in this research is considered as one of the potentially harmful social conditions contributing to the exacerbation of TB and diabetes for Cook Islanders. Parker and Aggelton (2003) make a call to rethink the frameworks typically applied to understanding stigma phenomena by attending to cultural complexity. Included in this rethinking is recognition of both individual and collective stigma. In chapter six, this thesis highlights the complexities of the stigma experienced by Cook Islanders with TB and diabetes in both the Cook Islands and New Zealand. In doing so this research builds upon the recent New Zealand based research in this area on the relationship between migration, stigma and TB (Anderson 2007; Ho 2003; Lawrence 2007; Littleton et al. 2008).

The case of the TB and HIV/AIDS syndemic

TB clusters where malnutrition, overcrowding, stigma and social instability exist (Antunes and Waldman 2001; Arras 1988; Farmer 2000; Freudenberg et al. 2006; Kwan and Earnst 2011; Marvidis 2008; Singer and Clair 2003). The majority of the TB related syndemics literature looks specifically at the interaction between TB and HIV/AIDS and harmful social conditions in the US. Even though HIV/AIDS is not part of this Cook Islands syndemic framework, similar harmful social conditions exist for Cook Islanders with TB and diabetes.

The history behind this syndemic provides a backdrop to infectious diseases being reprioritised in the developed and developing world. TB had vanished entirely from the health agenda of countries in the developed world and in parts of the Pacific, and has been replaced by higher prevalence of non-communicable and lifestyle diseases. The common perception is that Western countries were part of a natural progression through a conventional ordering of diseases influenced by social and economic development (Davis 1994). Through the lens of epidemiological transition theory, society is “seen as a sociobiological formation evolving through a number of pre-determined stages of development” (Davis 1994, p.172). The emergence of HIV/AIDS took the developed world

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14 TB accelerates and increases mortality from HIV/AIDS (Zhang 1995). Outside of the syndemics literature, but still connecting diverse elements of health, researchers have found evidence of TB and HIV/AIDS in particular (1)relating social dimensions of three factors being host, agent and environment (Selwyn 1993); (2) interaction of TB and HIV/AIDS with overcrowding and migration (Antunes and Waldman 2001); (3) interaction of TB and HIV/AIDS with malnutrition (van Lettow 2003); (4) TB and HIV/AIDS interacting with structural and political changes (Albalek et al. 2007); (5) TB and HIV/AIDS being symptomatic of an institutional isolation and lack of collaboration (Ravilgillone 2007).
by surprise, not only because of its communicable nature (beyond certain ‘sections’ of the society) but also because it fuelled the re-emergence of TB (van Lettow, Fawzi and Semba 2003). The rise of HIV/AIDS also highlights the need to contextualise the macro level changes which influence health, as well as human agency behind individual and household decisions. HIV/AIDS within a syndemic framework demonstrates that the inherent “assumption of inevitability” of the Epidemiological Transition cannot account for variation in historical and cultural processes nor human agency (Davis 1994, p.162). Within the syndemic literature Freudenberg et al. (2006) and Kwan and Ernst (2011) put forward compelling arguments that the TB and HIV/AIDS relationship demonstrates that multiple diseases combined with unequal social conditions magnifies the burden of disease and the overall risks of other syndemics.

**TB and diabetes in a transnational social field**

This study extends the literature on syndemics to include the influence that the transnational social field has on people’s health. Chapter one and two have set the scene, detailing the historical and contemporary relationships which have resulted in a unique set of mobility behaviours among Cook Islanders. Within the literature, connections between people’s physical space in terms of housing and access/barriers to health care are well documented (Baker et al. 2008; Cheer et al. 2002; Farmer 2000). There are also studies which connect the similarities of syndemic experiences of populations in different places (Farmer 2000). However, people’s relationship with the economic, political and cultural forces within the transnational social field can also be demonstrated to have an influence on people’s experiences of disease. Conceptually, this places the TB and diabetes syndemic within a network interacting with harmful social conditions and population mobility. A space exists where the connections and disconnections of politics, economics, socio-cultural behaviours and the environment can be seen as a powerful force upon the TB and diabetes syndemic.

Syndemic research provides a framework to interrogate the common assumptions within more traditional fields of bio-medical and social determinants of health research. This framework rethinks the separation of diseases into communicable or non-communicable categories and instead looks more deeply at the content of the connections between diseases. The intertwining biological, social and cultural processes of Cook Islanders are
positioned as both physical and social bodies with “on the ground” and “in the body” realities (Singer et al. 2011). This position removes the ‘blame’ of disease from the individual and shifts the main point of intervention towards the “large scale social forces” that “manifest in the morbidity of unequally positioned individuals in increasingly interconnected populations” (Farmer 2000, p.199). The importance of policy intervention is brought to the fore and with collaboration of better social and clinical monitoring it is seen to be the more effective way to intervene at multiple points (Candib 2007; Everett 2009; Littleton and Park 2009; Raviglione and Uplekar 2007; Wallace 1990; Ventura and Mehra 2007).

To understand people’s experience of a transnational social field and the interaction of both biological and socio-cultural factors upon them, a range of methods are needed. The disciplinary background of syndemic researchers influences their preference for types of information and analysis. Within the literature different modes of analysis are used. I employ both numerical and qualitative data from primary and secondary sources to highlight the effects the transnational social field has on Cook Islanders’ experiences of the TB and diabetes syndemic. Gathering accounts of how people’s beliefs and attitudes influence their health behaviours provides a stronger foundation from which to instigate prevention (Ng-Shiu et al. 2008; Singer et al. 2006, p.2020). To aid in my own personal understanding of the strengths and weaknesses of syndemic theory and its suitability for future development studies research, I purposely have included all traces of my methodology and analysis within this thesis. This includes my shifting conceptualisations of the TB and diabetes syndemic towards a TB, diabetes and transnationalism syndemic. This key characteristic of the research untangles the intricacies of both thinking syndemically, and arriving at a syndemic conclusion. Furthermore, this approach allows me to critically appraise syndemic theory as a tool for researching health inequalities amongst Cook Islanders.
CHAPTER FOUR
Practicing research and telling stories

A multi-sited ethnography recognises the influence of national boundaries but stretches the research gaze beyond national boundaries into a transnational social field (Levitt and Glick-Schiller 2004). Conducting research in a range of locations holds the promise of encounters in many different places; however, multi-sited ethnographies contain many logistical, ethical and analytical tensions (Marcus 1995, 1998). Issues of proximity and distance penetrated this research at many stages. The research story in this chapter highlights the tensions and strengths of multi-sited ethnography. Transnational research investigates the livelihoods, connections and relationships between two or more nation state arenas (Gielis 2011). The design of this research was complex due to the breadth of connections and processes which needed to be distilled into a syndemic framework. To tackle this complexity, guidance was sought from researchers who have undertaken transnational research in homes, cities or countries (Friesen, Murphy and Kearns 2005; Hondagnei-Sotelo and Avila 1997; Liki 2009) as well as those who have conducted research using multi-sited ethnography frameworks (Alexeyeff 2008; Connell 2009; Landolt 2001).

Overall, this research is a multi-sited study, acknowledging the “spatially and socially complex” lives of Cook Islanders, who are “mobile and multiply situated” (Marcus 1995, p.320).

In order to shape this research, a range of methods were used in an attempt to cultivate the meanings the participants attributed to their experiences of disease within a transnational environment. Simple summaries of the methods employed would distract from the reflexive position that time, space and place have had on the methodology of this research. The research story below guides the reader through an outline of the health specific Cook Islands transnational social field and reveals key connections within the TB and diabetes syndemic.

My research story

My research includes Cook Islanders with first-hand experience of TB, as well as Cook Islanders and non-Cook Islanders who live or work in close association with TB patients, and
other people with serious health issues. Case numbers of TB in the Cook Islands population in the Cook Islands and New Zealand are small; therefore a narrowly defined research subject focusing solely on TB would have proven difficult. Aside from the decision to employ a synergistic view of TB and the knowledge that diabetes was playing a role, I began with a loose research design which permitted me to include Cook Islanders with differential health experiences. Listening to stories about my family and reading the syndemic literature led me to believe that conversations about health would in some way link to either or both TB and diabetes. This proved to be accurate as TB and diabetes, in one sense or another, featured in either the background or foreground of the conversation with a range of participants included in this study.

Auckland is my residential home, and the place where this research began. More Cook Islanders reside in Auckland than anywhere else in Cook Islands and New Zealand, and the Auckland region is the largest provider of health services to Cook Islanders. The health of Cook Islanders who are in Auckland permanently, transitonally or momentarily to access health services is served by three of the largest District Health Boards (DHBs) in New Zealand. Therefore before embarking on the collection of experiential accounts I began my research by tracing an outline of the health services available to Cook Islanders with TB. Interviews and informal conversations were held with key stakeholders in the area of tuberculosis diagnosis, treatment, surveillance and strategic management planning. This included the Auckland Regional Public Health Nurses (PHN), the Auckland Regional Public Health Services Chief Medical Officer, Pacific Liaison for the Auckland Regional Public Health Service and the Counties Manukau District Health Board and Biomedical Technicians at LabPlus. A lengthy discussion was also held with the Counties Manukau District Health Board with regards to the MOU\textsuperscript{15} between them and the Cook Islands Ministry of Health.

Given that Cook Islanders are more likely to live in or visit Auckland than anywhere else in New Zealand, over time advocacy and leadership organisations have been established to promote health and well-being amongst Cook Islanders living in New Zealand. The hub of these groups is typically based in central or south Auckland. The Cook Islands Health Network Association (CIHNA), established in 2004, is an important networking and

\textsuperscript{15} Refer to section on Contemporary health ‘partnerships’ in chapter two for more details.
advocacy group. The role of this charitable organisation is to connect people of Cook Islands heritage within the health sector in New Zealand and to promote an increase in the health work force capacity of Cook Islanders. In this study, CIHNA played both a connecting and advisory role throughout the field research stage.

My research in the Auckland health services and the Cook Islands community provided an overview of the connectors within the health realm of not only TB but Cook Islanders generally. Names of key people would constantly be repeated, not just in their official capacity, but because of the services they were providing at a community level. During this process I was able to identify key places and people of significance in terms of TB screening/diagnosis, contact tracing and treatment. Exploring these places highlighted that what binds the multiple elements of TB as a disease is the Public Health Nurse (PHNs). These people deliver Directly Observed Therapy (DOTs) and connect the dots that surround people’s experiences of TB. Given the significance of this group of people, before interviewing could begin the assistance of the Public Health Nurses was critical. I approached the PHNs to see if they would agree to signal my interest in conducting research with Cook Islanders who they were treating/had treated. If an interest to participate was identified, with the potential participants’ permission, I was then given access to their clients’ contact details. Place is a determining factor in the treatment of TB, with each PHN designated to cover a particular geographic area. Accordingly, this means that PHNs have differential expertise and an awareness of those most vulnerable to TB, given that they tend to cluster in certain areas. Because of the higher number of Cook Islanders resident in the suburbs of Glen Innes, Avondale and Otara, three PHNs working in these areas connected me with the Cook Islanders who would become participants in my in-depth health interviews. Over the course of two years I formed a particularly strong working relationship with the PHN who works in Glen Innes. She allowed me to observe her working life at her office, in her car and in the homes of some of her clients. The access and information granted by this PHN was reciprocated by my developing an understanding of the challenges of the job of a PHN and a deep appreciation for the wider service these people provide to families.

Health research is problematic as participants are usually identified and recruited because they are experiencing some form of physical difficulty. The desire for personal privacy,
experiences of shame and lengthy treatments make the process of participant recruitment all the more difficult. Often my searches would lead to dead ends, and at times the waiting seemed tiresome; however, each failed attempt made it clearer that the stigma of having TB is real, and that it is, most certainly, a disease of poverty in New Zealand. The stresses and symptoms of surviving on limited resources become a key obstacle for Cook Islanders (Lawrence 2007). A researcher in this environment must tread very lightly, slowly reassuring people that one's motives are good, and that all precautions to limit possible harm will be taken. Beyond taking the necessary precautions for dealing with those with serious health conditions, I was mindful of the social and cultural constructions of Cook Islanders' experiences with disease (Mila-Schaaf 2009).

Frequent contact with the PHNs was needed to remind them to keep this research in mind despite their hectic schedules. This contact was also an opportunity to reassure them that I would treat their clients with respect. PHNs delivering DOTS into people’s homes become protective of these people as they form a daily relationship with them over long periods of time. The difficulty I faced in the recruitment of people with TB provided the impetus for me to extend my understanding of research ethics beyond standard university guidelines. These guidelines are not culturally nor conceptually sensitive for research with Cook Islanders who had serious health conditions. Reading more widely on ethics alerted me to similar concerns researchers share about protecting their participants, and indeed themselves, in areas of sensitive research (discussed in greater detail below). Overall, I came to understand that nurturing a small selection of participants would enable me to better care, protect and value the stories they shared with me.

In-depth interviewing (see below for a full description) was my primary research method throughout my two years of fieldwork. The decision to rely heavily on the information gathered during these interviews and observations rested with my intention to use the stories to construct a realistic portrayal of living within a transnational social field. I also believed that the narratives of the participants provided a viable way for me to explore the strength of the syndemic connections. From the outset, I imagined that interviewing would enable me to get a sense of the interacting factors contributing to a person’s experience of disease. For a syndemic framework to be applied, careful attention needed to be placed on both hearing and observing the multiple forces at play which impact a person’s health. My
earlier research in the Cook Islands also demonstrated that although questionnaire-based research is useful for some forms of information, Cook Islanders are more comfortable relating their life stories in the form of conversations. These frequently include stories of family histories, personal relationships and local politics (Marsters 2004). The stories, whilst significant in their own right, also speak broadly to the experiences of other participants. These stories were recorded on a tape recorder and transcribed at a later date.

From the start of my in-depth interviewing I dedicated considerable time to writing notes that captured the flood of information I gathered in these settings. This provided me with the opportunity to ‘talk’ through these notes in my mind, solidifying the memories to ensure little was lost between the interview and the time I got to my computer. Writing these notes also provided a good opportunity for me to contextualise my experience.

In Rarotonga I attempted to mirror the research process carried out in Auckland. Rarotonga is the location of specialised and secondary health services, and today the Rarotonga hospital is also the main liaison point for Cook Islanders from all islands who receive referrals for health services in New Zealand. I made two research visits to Rarotonga. The first, research trip in 2010, allowed me to meet with the Minister of Health and Tupou Faireka, then Secretary to the Ministry of Health. In addition I also met with Dr Rangi Faireu, Director of Public Health; Nuks Pokura, TB Project Coordinator; Karen Tairi, Nutritionist in Public Health; Heather Aitu-Webber, then manager of the Rarotonga Hospital; and Wilkie Rasmussen, then Secretary to the Culture Department. Overall, my main purpose for this visit was to begin to establish relationships with people in the Cook Islands who would later play an important role in assisting elements of my research. During this brief visit I was also able to participate and observe at a diabetes clinic in Tupapa and introduce myself to some of the nurses and doctors. The trip was an excellent signifier that there would be a lot to achieve during my longer research period and that my limited time would need to be used very wisely.
I arrived in Rarotonga in August 2010 for the second eight-week stage of field research. My first week of research was dedicated to the recruitment of participants. On the advice of a close family member, who was a registered nurse at the hospital at the time, I approached Tupou Faireka (Secretary of Health) for local approval from the Ministry of Health for my research. Tupou ‘blessed’ my research information form, which proved to be invaluable throughout my time in the Cook Islands. The respect and authority of Christian values was explicitly used to convey my legitimacy to carry out my research. The ethics consent process, which in Auckland had worked without any tension because of the frequency of formal consent being sought in health matters, needed some form of local contextualisation for Cook Islanders in the Cook Islands to be included in the study. It is important to note that contextualised approval in the form of a blessing was used alongside the research approval that had already been sought from the Government of the Cook Islands Prime Minister’s Office, The Auckland District Health Board Research Review Committee.\(^\text{16}\) A National Application for Ethical Approval of a research project was

\(^{16}\) RRC 01/09/08
completed by the Principal Investigators of the ‘Transnational Pacific Health through the Lens of TB’ project. In combination, the approval from these bodies and governments provided ethical research coverage to all of the researchers within the large multi-disciplinary study. In the section below, I provide details of the ethical considerations I undertook during my PhD research.

My first week-long visit to Rarotonga indicated that finding people with a history of TB would be difficult due to both low case numbers and the stigma attached to the disease. The willingness of Karen, the nutritionist, to put me in contact with people with diabetes enabled me to explore the reality of people with diabetes as well. I reintroduced myself to key officials and also visited people at the National Council of Women and the Red Cross. I reminded them to think of me if anybody they knew might be willing to talk to me about their experiences of TB. I was not deterred by people often saying “no, no one has TB anymore”.

The level of trust established between myself and the PHNs in Auckland led me to make considerable effort to form relationships with the PHNs in Rarotonga. Unlike in Auckland, where I had been well received, I initially found it difficult to establish trusting relationships with the local nurses. Later I learned from one of the nurses that the PHNs are wary of research and possible scrutiny. Eventually I formed a good relationship with one nurse, Mona, who had had some responsibilities with TB contact tracing in the past. I had previously met Mona in Auckland while she was on a TB contact tracing course. The PHNs in Rarotonga, particularly Mona, made themselves available for me to spend entire mornings at clinics in the villages and preschools. As in Auckland, Mona was responsible for the public health of a designated geographical area, which in the case of the Cook Islands is a village. During our time together, I was able to gain a greater understanding regarding the health of people in her remit, Arorangi. The women, babies and young children would gather at the designated clinics to have their babies weighed and checked over by Mona. It was during these times that Mona would enquire about people in the village, constantly adding to her log of information regarding the health of people under her care.
After a week in Rarotonga I reached a point where I was able to interview at least one person a day. I gained the contact details of these participants through the PHN Mona, people at the Ministry of Health, the National Council of Women and the hospital. I also interviewed others who were identified during my first research trip. These interviews were conducted with people in an official capacity or people with health and mobility stories. Interviews were organised over the phone and I travelled to meet people by car. Often the interviews were performed at work. When an interview occurred in a person’s home, it allowed for additional observations to be carried out. Petrol shortages were in place during this time, so travel and interviews were designed to dovetail into each other.
These petrol shortages served as an important reminder that in the Cook Islands, supply and demand forms an asymmetrical relationship. This event made me consider the vulnerability of the Cook Islands with regards to the supply of, and demand for medical professionals, medical equipment, diagnostics and pharmaceuticals. Labour and goods are crucial strands of the transnational field and like petrol, how these strands connect depends largely on the functioning of multiple governments, aid agencies and shipping companies. With this in mind, an image of the Cook Islands health system as a fragile ecosystem began to emerge.

Unlike in Auckland, where it was easy to go back and forward for multiple interviews, interviews in Rarotonga were individual and ran for approximately an hour. In Rarotonga, I was unable to interview anyone with a current history of TB, although there were interviews with people who assisted in the care of family members with historical TB. The majority of my participants had diabetes. One participant had recently returned to Rarotonga after a lung transplant operation in Melbourne. This participant had serious bronchiectasis. Although this participant had not suffered from either diabetes or TB, I performed the
interview with interest in his health and mobility patterns between New Zealand, Australia and the Cook Islands.

After four weeks in Rarotonga I travelled to Aitutaki. I had prearranged to meet with Metua, a PHN I had met in Auckland while she was performing some TB contact tracing training. Metua had responded to my emails and was happy to assist my week-long research stay in Aitutaki. My first stark impression of Aitutaki was that the structural wounds from cyclone Pat in February 2010 were still very evident. Half-finished concrete dwellings sat alongside flimsy white tents where people still lived. The island, which is usually abundant with fresh fruit and vegetables, was experiencing shortages of both. In most places the orange-brown topsoil was still bare.

Aitutaki is renowned for its lagoon beauty; however, I found it hard to take in the beauty of the lagoon when I saw the expensive resorts juxtaposed with locals living in extremely vulnerable conditions. Such vulnerable conditions were a motivating factor for me to travel to Aitutaki for research. Natural disasters have implications for mobility, displacement and health. Aitutaki had not experienced the combined misfortune of high incidences of infectious disease that often accompany recovery from natural disasters in developing countries, yet I sensed that the cyclone would have caused high levels of stress within many of the households, particularly those who had lost their home. Before meeting with Metua I spent some time with the Island Secretary and enjoyed a morning tea with the rest of his staff. I also interviewed the Island Mayor, Ta’i Herman who was able to share many interesting details on the barriers to recovery that Aitutaki was experiencing. In addition to his role as Island Mayor of Aitutaki, Ta’i Herman was a local advocate for the disaster relief and rebuild, and told many accounts of the obstacles Aitutaki was facing in terms of supply. Basic household commodities were becoming expensive for people as demand for imported goods had grown with the agricultural disruption. Materials had arrived from Australia and New Zealand to provide shelter for some of the families; however, there was a shortage of both tools and labour to get these completed.

On my first day accompanying Metua on her work schedule I was given a tour of the hospital, which consists of a 22 bed ward, one surgery and one maternity delivery suite.
Mama Ki’i\(^{17}\), a nurse in the hospital, shared many memories of the 1950s TB epidemic with me. Metua was also able to connect me with two participants, one historical and one recent case of TB. Both participants also had diabetes.

In Aitutaki I experienced some difficulties with language. Maori is the main language spoken, and although I had become familiar in Rarotonga with using simple words to translate medical jargon, in this context, I had to rely heavily on Metua to act as a translator between myself and the participants. Metua, in her capacity as a PHN, had experience in transcending different languages to elicit information relating to a person's health. I learnt many new phrases from her. When asking about 'stigma and TB', I learnt to ask if "you are shy of Maki Maro" (Cook Islands Maori for TB). Language was not the only defining characteristic of my time in Aitutaki. I also experienced a different reaction to talking with me. In Rarotonga people had appeared hesitant and needed time to warm up, while in Aitutaki, there was a genuine openness to talk. I asked Metua about this, and she informed me that Aitutakians are known for being cheeky and open. Aside from a cultural disposition I also associated this openness with the slower pace of life on the island. The distance between Rarotonga and Aitutaki is small in comparison to the other dispersed outer islands; nevertheless, the differences between the two cultures in Rarotonga and Aitutaki were apparent.

*Research diary entry 7th October 2010*

I was lucky that Metua introduced me to a Papa that had had TB in 2007. We simply drove up to his house and he was sitting under a tree. He seemed happy to talk to me, in fact he enjoyed the opportunity to joke around with both of us. Again the ethics form was problematic. I felt as though I was making a big deal out of chit chat. Metua explained it well on my behalf and I felt very grateful for her being able to translate my English so that he would better understand. The flip side of this is that at times I felt out of control of the interview. I was lucky that Metua understood my interests well and was very interested in TB.

\(^{17}\) Pseudonym
Pacific peoples, including Cook Islanders, reside not only in Auckland but in other parts of New Zealand as well. I was curious about how the transnational social field stretched to and operated in places outside of Auckland. Following this curiosity, I travelled to Wellington and Porirua in September 2011. CIHNA had put me in contact with a Cook Islands social worker who worked out of the Fanau Centre in Cannons Creek, Porirua. She had been welcoming over email discussions and believed that she would be able to help introduce me to people with health and mobility stories. There was also an opportunity for me to meet with representatives of the Ministry of Health in Wellington, the New Zealand Aid Programme (formerly NZAID) and the Pacific Paramedical Training Organisation.

The overall result of these transnational research journeys was a range of recorded interviews and large amounts of notes which spoke to the intertwining political, economic, medical, cultural and family elements of TB and diabetes. Out of the 40 interviews conducted for this study, 19 of these were in-depth health interviews. At times a series of interviews were held with the same participants. These multiple interviews provided the

\[^{18} To extend my understanding of the transnational social field I also interviewed a number of policy people whose roles connected to the lives of Cook Islanders’ experiences of TB or other disease.\]
parameters for building rich case studies/stories of the lived health experiences of Cook Islanders.

**The research tool kit**

Researchers use many tools to look at the key events, relationships, external and, in this case, internal biological forces that are part of people’s lives and experiences. This research prioritised the problem of the TB and diabetes syndemic over specific disciplinary concerns in a transdisciplinary fashion (Leavy 2011, p.14). I committed to using a range of tools, and as such, my research is designed around paths, threads or juxtapositions and break down the dualism of ‘them’ and ‘us’ research (Marcus 1995, p.100). Transnational research in multiple locations allows for less stark comparisons to be made between ‘them’ and ‘us’, and site A and site B, and instead emphasises shades of landscape or space where the actual lives of people can be situated. The size of the Cook Islands population and a keen interest in people’s lineages also revealed the family and situational connections between my participants. My own position as a researcher and a Cook Islander shifted constantly, and the connections between my participants reminded me of the overlapping positionalities inherent in the research process. For example, as the New Zealand born daughter of a Cook Island migrant, my identity is constantly in flux. My dynamic identity and the fluidity of my movement have produced particular life experiences, which according to Dyck, not only shape a researcher’s fieldwork, but also “enable particular kinds of insight” (2000, p, 36).

Dialogue was both the medium and the outcome of my research process. By collecting stories of people’s experiences of health I believe I collected the accounts in the most appropriate way, but I am also committing to my belief that the audience of research needs to include the participants themselves (Brettell 1993). I believe it is important to have an “ongoing productive conversation” in the area of Pacific health, and using the stories themselves as a key communication tool widens the audience to include a range of people, both inside and outside of the academy (Fischer 1991). Throughout the research period, I honed a set of tools that could provide me with social representations of Cook Islanders living with disease. The guiding intention was to capture life stories as a way to trace people’s movements, relationships and experiences through time and space (Bell 2001; White 2000). The life story approach does not focus on one aspect of a person’s
experiences but instead on the series of events that influence their lives (Angrosino 2002). Kothari asserts that “life histories and narratives articulate continuities through the telling of events and experiences over time and highlight how subjective and collective understandings of past and present are imbricated” (2005, p.53). Life stories and narratives also offer the opportunity to uncover the social contexts of meanings, languages and personal and institutional culture (Kothari 2005). An important dimension to life stories is accurately capturing the details of peoples’ lives. In this study, the details of travels to other places, important family events such as births, deaths and marriages, as well as the diagnosis and treatment of disease were all recorded in a systematic matter. Once consent had been gained from a participant I would also validate my information with medical records or the Public Health Nurses (PHNs). Occasionally there were discrepancies, but mostly these medical records spurred on new lines of enquiry. In this way, the primary and secondary modes of this research were iterative instead of linear. Over the course of several interviews, I was able to get to a sense of people’s health experiences, which to some extent had become “taken for granted behaviour” (Dyck 2000).

The social construction of the interviews conducted was never far from my mind. Fischer alerts us to be aware of “who is constructing the account, why, how and for whom” (1991, p.25). Eventually, I became adept at building participant profiles in my mind during interviews, signifying key characteristics of the person that defined them from my other participants. This initiated an important part of my coding practice and would later inform my analysis. Whilst in the beginning I was nervous that people would be unwilling to share their private health matters, I discovered an open willingness to share their stories. For some participants it was a cathartic experience; a sympathetic, unbiased ear for people to talk to about their health and health service experiences (Kearns 1997). All attempts were made to form a social relationship with my participants and I worked hard to allow the story to be told and directed by the subject (Etter-Lewis 1991). I was guided by Leslie’s belief that:

Truly personal engagement, developed with those among whom we cultivate research relationships, collapses ‘difference’ and emphasises shared humanity, while highlighting unequal privileges and disparities (2005, p.284).
These life stories were commonly recorded in Cook Islanders’ translocal\(^{19}\) houses (Gielis 2011, p.260), and were situated within the “home field” (Dyck 2000). The idea of a home field relates to the idea of a social field (Levitt and Glick-Schiller 2004) in that it makes ‘home’ far less a matter of birthplace or nationality than of continuing personal engagement in certain types of social aggregations, activities and relationships (Dyck 2000). Spending time in people’s homes, allowed me to get to what Marcus refers to as the “white noise” in the setting (Marcus 1995, p.111). For me, this “white noise” was the health related behaviour that had become a routinised feature of everyday life (Garro 2010). These behaviours may have been as obvious as levels of hygiene, types of food eaten, dressing appropriately for the weather or the organisation of medications to be taken sporadically or daily. English was the main language, although at times when a nurse was present Maori was also spoken and then translated back to me.

There is a strong interaction between housing, poverty and disease in this study. The decision to carry out participant interviews in people’s homes was not incidental. Kearns et al. (1991) asserts that disease is not in the dwelling itself. Rather, the social and economic realities of deprivation are played out in these places. From this perspective, I was able to shift my thinking from TB transmission as a result of overcrowding towards the mechanisms which also foster the clustering of diabetes (Baker et al. 2000; Tukuitonga and Finau 1997). Singer (2009) views TB as the menace of urban life in developed countries with inadequate housing, and crowded living conditions have long been associated with increased infectious disease transmissions (Baker et al. 2000). The inadequate housing of Cook Islanders in New Zealand, and temporarily in Aitutaki post Cyclone Pat was evident for many of my participants. Signs of housing inadequacy included lack of space, broken windows in winter months in New Zealand, broken furniture and mould. However, the more powerful representations of housing and how this related to Cook Islanders experiences’ of disease was contained in their personal accounts of the inability to pay for heating, lack of privacy because of the numbers of people living together and also the vulnerability and powerlessness of renting accommodation off the state. Of all of my participants, very few were landowners of the property where they were living. It was not the lack of ownership

\(^{19}\) Cook Islanders homes are ‘translocal’; they are the meeting place of (cross border) social processes (Gielis 2011, p.260).
that I could see playing a role in their overall wellbeing, but more the reliance upon other people to provide them with a place to live. In New Zealand, the absolute essential need for money to pay rent was also stressful (Prior 1989). In both countries “not having a place to call home” as a result of poverty, natural disaster and high levels of mobility could be seen to impact on the overall quality of life of unwell Cook Islanders (Kearns et al. 1991).

Recording the stories of people’s experiences as they relate to health is a common mode of enquiry for social science researchers (Cheer et al. 2002; Kearns 1997; Milne and Kearns 1999; Lawrence 2007; Leslie 2005; and Underhill-Sem 2001, 2002). At the core of this method is learning how to listen to the “narratives found in the contexts of everyday life” (Kearns 1997, p.273). By learning how to listen and ask relevant questions, Macdonald and Park (1999) argue that it is possible to understand how people construct ideas about their bodies and their health related practices (Macdonald and Park 1999).

Observing people and health

Along my journey, observation became not only a key method of research, but also a heightened sense of awareness when in the field. My awareness was heightened with regards to my own position in the field, and the environment around me. I would observe everyday life in homes, places of work and general society, and if possible, I would ask people questions while they carried on with their daily lives (O’Reilly 2005). Emerson, Fretz and Shaw (1995) describe this process as “getting close” to people. It is also a process of getting close to places. Often my participant observation aligned itself with getting to know a potential key participant and places important to those living with TB and/or diabetes. I spent many hours with PHNs, health promotion staff, and clinic nurses, sitting in the back corners of doctor’s surgeries and hospitals. This allowed me to diminish some of the space that exists between the researcher and the researched (Thaman 2003). Becoming familiar to the staff and the patients in these settings was important for this research to be successful. I felt myself move from a position where people would look at me as ‘Evelyn from the university’ and eventually towards being ‘Evelyn, niece of Stella, talking to people about diabetes and TB who I saw yesterday at the beach with her family’. There are always moments in time when you know space has slightly diminished. For me, it was arriving at a clinic to a freshly made ei katu (head garland), a nurse paying for my coffee or arriving at a
participant’s home to find that all efforts to present the house for my arrival had been forgotten.

**Focus groups research**

Focus groups are used throughout the social sciences as a means to “elicit people’s understandings, opinions and views, or to explore how these are advanced, elaborated and negotiated in a social context” (Wilkinson 1998, p.187). I used a focus group in this research on one occasion. During my field work in Porirua, time constraints meant that my usual method of using participant observation to build relationships with future participants was not possible. I was fortunate enough to have a social worker who organised a group of people to meet me so that I could tell them about my study. This group was set up as a meet and greet, but turned into a focus group almost immediately. The group that the social worker assembled all had experiences with diabetes. Some of the members also had historical experiences with TB. The conversation with six people lasted roughly two hours. While focus groups can interrupt or limit a person’s narrative it does provide an entry into something which is often lacking in private interviews; such as how people relate their own experiences of health to their family and their community (Hyden and Bulow 2003). The focus group in this research highlighted the wider role and experiences of husbands and wives when living with someone who has diabetes. In this focus group, four out of the six were married, and it became clear that partners play an important part of ensuring that treatment is adhered to, and that necessary lifestyle changes can be made. Partners conversely were also seen to contribute to the shame and embarrassment suffered by a person with diabetes. This focus group provided background knowledge on the Cook Islands community in Porirua and the transcribing process indicated that it would be valuable to revisit two participants for in-depth health interviews. Two subsequent visits to Porirua were used to perform these interviews and to keep in touch with the participants of the focus group.
Ethics across a transnational social field

Prior to embarking on the first stage of my field research in the Cook Islands I packed up my tape recorder, my computer, my knowledge of ethnographic field techniques and a list of contacts. I made sure I clutched tightly to my partial Cook Islands heritage. What was missing from this transportable research suitcase was my own defined set of ethical principles. This is not to say that my research was performed without ethical consideration. Instead, as I moved in and out of places and travelled from conversation to conversation I discovered that a silent reflectivity was occurring, and that I was steadily establishing my own set of ethical principles.

Transnational health research confronts the inflexibility of biomedical ethical application procedures in multiple research settings. When I moved into the field, I was jolted by how inappropriate my theoretical understanding of ethics was from a practical perspective. On reflection, what I needed was a more practical guide. This section provides an evaluation of my own research experiences and how they relate to research ethics.
One of the first and guiding questions that researchers ask themselves during this process is: who benefits from the research? (Scheyvens and Leslie 2000). The design of my research project reflects my belief that research should reach a wide audience, inform policy, and endeavour to influence change. This position aligns with the principle of utility, which can be defined as explicitly linking “research and its findings with tangible improvements in health outcomes” (The Health Research Council of New Zealand 2004, p.29). The previous section on my methodology emphasises my desire to build solid relationships and I recognised that this principle of utility should not change across national borders. My methodology also highlights how research needs to cope with many more relationships and include multiple interpretations of what will usefully inform health outcomes.

Alongside the principle of utility, mutual advantage of the research was promoted as fundamental to my research process. For mutual advantage to be actualised we must begin our research relationships from a position of what we can offer, not what we want to take. In the Cook Islands I offered my experience as a policy analyst to key informants in exchange for information and access to people and places. It is important to note, that in the Cook Islands such a gift cannot be fixed in terms of an expiry date. People need to be assured that the offer of assistance extends for a time period after you have retreated from the field. I now think about balance and mutual advantage in terms of short, medium and long term advantages to accommodate the expected outcomes and constantly fluctuating social relationships you create during your research. Symmetry of power will not always be possible as we step into different worlds where gender, hierarchy and politics all have different meanings. Mila-Schaaf’s advice of thinking in terms of “mutual advantage” (2009, p.138) was helpful in this regard. I wanted to ensure that the process of being interviewed was beneficial to my participants in some form. For example, for a person with health concerns I wished to listen carefully to their issues, convey a sense of empathy and in most cases I was able to help them to understand the disease they had more clearly. Speaking at length about TB and diabetes allowed the participants to ask questions they had either forgotten at the time of their consultation with doctors or nurses, or questions they had been too embarrassed to ask. For PHNs, policy and government workers I was able to share my observations and findings, which in many cases dovetailed with their similar research interests at the time.
During this research I was also mindful of the need for balance between the researcher and participant before entering into a relationship. In different Pacific cultures, reciprocity takes on different meanings. I had to reflect on my intention to reciprocate in culturally appropriate ways by thinking through what the protocols were for reciprocating with people of different ages, genders, marital status and status within communities. Researchers are often led to believe that it is always the researcher who offers something to a participant to compensate for their participation. However, this ignores, that for some people and groups, they may value their inclusion in the research and offer you something to demonstrate their appreciation. In the Cook Islands I received many ei katu (flower garlands), invitations to kai kai (feasts) and other cultural events. Moreover, people’s willingness to talk to me about their social, familial and health events and experiences led me to believe that the process was therapeutic for them. I do recognise that for some, this process could be difficult and cause emotional distress.

A central concern of studies involving research with human participants is protecting their safety and dignity. The most common way that researchers ensure that participant’s rights are protected is to inform them about the research (and any risks that may be involved) and then seek either written or verbal consent. This convention allows partial ownership and risk to be devolved to the participants themselves (Caplan 2003; Hudson 2009). Once in the Cook Islands I found the practice of asking for formal consent uncomfortable. This was because for many participants, agreeing verbatim to be included in the research signalled their consent. Therefore, when I came to ask for consent, it often interrupted the conversation. On other occasions, asking for consent appeared to place a barrier between myself and the interviewee and at times there was resistance to continue with the interview. Research as a form of social relationship has had different consequences for Pacific people, and this resistance brings to mind instances where Pacific people have been presented negatively or where research has not been shared fairly (Mila–Schaaf 2009; The Health Research Council of New Zealand 2004). After I came up against this resistance a few times, I decided to ask one of my key participants about it. She pointed out that despite having received ethics approval in New Zealand such consent was not recognised by everyone as allowing legitimate access to interview some people. Instead some participants may have
needed to know that the senior officials in the Ministry of Health were ‘allowing’ them to talk to me.

In the New Zealand field, where forms and procedures are more common, asking for consent within the confines of the family home was more straightforward. In the public offices of the New Zealand government however, there was a level of hesitancy in signing the consent forms and agreeing to the tape recorder being used. These people speak not only privately but also on behalf of public offices. These examples not only demonstrate the diversity of place-specific experiences involved in seeking informed consent, but also that informed consent often goes beyond the individual.

In both Rarotonga and Aitutaki I spent considerable time at mother and child clinics. These clinics serve an important function in the village. They provide the PHNs with an entry into the health of the families in the village as the mamas attend and share what is going on with their families. The clinics also serve to celebrate and reward the effort that parents put into nurturing their young children. While in these clinics, I asked the nurse if she would ask those in attendance if it was ok for me to attend, listen and take photographs. The nurse acted as an intermediary and was able to translate the official and academic languages into a familiar mix of English and Cook Islands Maori. If a person turned up late, the nurse would introduce me and explain to them why I was there. No forms were signed, instead, those who were comfortable with my presence continued with their conversations. Those who did not want to share, were allowed the right to not participate and were also able to save face by talking to the intermediary instead of me in Cook Islands Maori.

Researchers with informed consent forms and participant information sheets enter into a distinct social relationship which, while I was in the Cook Islands, meant very different things to different people. The above experiences indicate that the common convention of receiving informed consent from your participants needs to be contextualised (Benatar 2002). During my research in Rarotonga and Aitutaki in 2010, protecting a participant’s confidentiality was the most challenging ethical practice I had to deal with on a daily basis. Word of your work quickly circulates in a small place. I had envisioned my research identity as being “Evelyn who is talking to people about accessing health services”. An identity was devised as a way to disguise the TB and diabetes elements of my study in an attempt to
protect my participants from any (or increasing) stigma. However, within a week I was often referred to as “Evelyn from the University of Auckland doing TB”. This is reflected in the number of people willing to talk to me, but also meant that those who did (who most likely did not have TB) could come under suspicion for having a serious communicable disease. Interestingly, when I travelled to a smaller island, Aitutaki, where privacy was almost a novel concept, people were willing to talk to me and were not bothered about people knowing their health history, because people already knew. The overall issue of confidentiality in this study contributes in part to the decision to represent the case studies as illustrations (see chapter five). In this way, the material is conveyed visually, with images used to tell the private stories of people’s experiences with disease. The emotive images add another protective layer of anonymity from the text. It should be noted, that one participant actively promoted the use of his name, in the hope that his story would inspire people to make better health decisions. Because of his prominence in Cook Islands society, he believed that his story could make some impact.

In the Cook Islands, confidentiality is akin to privacy, and privacy is hard to secure in a small island. The use of pseudonyms offers little reassurance to a person who lives in a community of only a few hundred people. If the text is rich with examples, narratives, and descriptions it will be very obvious to others in the community who is being written about. What can we do when the issue of confidentiality is particularly relevant such as in the case of talking to people with experiences of disease? Stigma is very real for some people with disease, and exposing their private health status in small communities can have long lasting and far reaching effects for not only those with the disease but also for their family.

Privacy and confidentiality is approached differently in New Zealand. Obviously the scale of a city like Auckland and Wellington assists significantly in protecting the privacy of those undergoing TB treatment. Whilst shadowing a PHN in Auckland for a day I noticed that the nurse was always in plain clothes and the car was unmarked. The design of the nuclear house in New Zealand also serves to confine personal matters to inside the four walls. Replicating village life is difficult when you live in a suburban setting. When I arrived at peoples’ houses to interview them, neighbours and children would notice me. I was not “Evelyn doing TB research” as I had been in the Cook Islands. Rather, I was just another
government type”, a familiar presence in Glen Innes, Otara, Avondale and Porirua. My own anonymity served to provide protection for my participants.

The research approval for my research in the Cook Islands was sought by the Principal Investigators of the “Transnational Health in the Pacific through the Lens of TB” research project during an earlier research scoping trip. The agreement between myself and these team members was that I would visit the Prime Minister’s Office, introduce myself and talk to the administrator concerned about my research. The administrator remembered me from my Master’s research and we had a long discussion about the process of research approval in the Cook Islands. She acknowledged that there was no specific place within the research form to deal with ethical considerations. It appeared that the Cook Islands rely heavily on the notion that ethical principles need to travel with researchers. Underpinning The Pacific Health Research Guidelines is the belief that research guidelines, including the ethical principles and practices of the nation “lies with the Pacific nations themselves” (2004, p.1). The guidelines therefore share a similarity with other ethical approval procedures in that they are firmly attached to a disciplinary or a geographical boundary. I believe it also introduces an opportunity for Pacific nations such as the Cook Islands to think about developing culturally specific ethical and cultural guidelines for researchers.

The field experiences above illustrate the overlapping and interdependent ethical principles I have adopted. The final, and in my opinion, all-encompassing ethical principle is that of respect (Scheyvens and Leslie 2000). Respect encapsulates the upholding of rights, the appropriate use and ownership of knowledge and sharing the fruits of our endeavours (Kuwayama 2003; Pham and Jones 2006; Mila-Schaaf 2009; Scheyvens and Leslie 2000).

As I conducted my research, ethical tensions challenged my own understanding of my research and myself as a researcher. My movements to date have helped me to build a deeper understanding of the contextualised nature of ethical principles which in turn influence my practice. Researching in multiple locations has forced me to consider the multiple voices in my work (Caplan 1988; Kuwayama 2003; Scheyvens and Leslie 2000; Sumner 2007). While the literature on ethics and the process of seeking ethical approval goes some way to prepare researchers for the field, new researchers like myself gain most of their understanding when they can hear, touch and feel the ethical tensions in their work.
As I move through places and spaces in the search for new knowledge and understanding it becomes clear that research experiences illustrate the interplay of cultural identity, research positionality and ethics.

**Analysis**

Emerson et al. (1995) believes that theory combined with a researcher’s disciplinary background exert influence on the way in which you ‘unpack’ your data and the way in which you put it back together. Throughout the research process and the production of this thesis there is the interplay of transnationalism theory and syndemic theory. My previous degrees in geography mean that ‘place’ is significant to me (Underhill-Sem and Lewis 2008; Kearns 1997), and my position within development studies forces me to consider the inequalities surrounding my participants (Macdonald and Park 1999; Makaiale, Patterson, Silipa, Tupou, Agee and Culbertson 2007; Leslie 2005; Littleton and Park 2009; Underhill-Sem 2001, 2003). There are explicit and implicit connections between these elements of my research, and these connections form the basis for my initial engagement with my data. I systematically asked a number of questions about my data, informed by the initial memos I wrote at the end of each transcription, or at the conclusion of a participant observation exercise (Emerson et al. 1995). This process produced a heuristic, which, you will notice privileges the syndemic orientation of my research. The bio-cultural contexts of TB and diabetes are complex and multidimensional. Therefore, in order to find a way through the many nuanced accounts of Cook Islanders’ health experiences I designed a heuristic explicitly relating to the syndemic conditions that this thesis focuses on.

Syndemic theory concentrates on the seemingly invisible points of contact between the social and cultural conditions and co-morbidities that interact to create a disease or worsen the symptoms of a disease(s) (see chapter three). Both syndemics and transnationalism theories are relational and the heuristic below illustrates that while defined connections within syndemic theory are important, transnationalism reminds us that “experiences do not arise in a social vacuum” (Gielis 2011, p.262) and a myriad of socio-cultural relationships affect the experiences of people.

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20 Heuristic “a set of broad questions to ask about the texts” (Emerson et al. 1995, p.30).
The set of questions below served as a guide through the interviews and post interview note writing:

- What is the socio-cultural position of this person? Are there harmful social conditions? How does this relate to their health and experiences of health service access?
- What is the mobility history of this person? How does this relate to their health and experiences of health service access? What social and biological connections has this mobility resulted in?
- Does the person make comparisons between health in multiple places? How do they relate their physical and emotional ‘place’ to their health now and in the past? What is their ‘explanation’ of their disease/diseases?
- Does this person have diabetes and TB? How does this relate to their health or health service access? Does this co-morbidity increase the burden of the disease for this person?
- Are they narrating their own health experiences or are they talking about other people as well? Is this health story multidimensional? What social-familial connections surround their health story?

Numeric data is used in positivist disciplines to provide evidence of phenomenon. Epidemiology is an example of one such discipline, which according to Plumridge “cannot investigate the mechanism by which health behaviour (and therefore health status) is currently generated and structurally maintained” (1999, p.23). Plumridge does not discount the valuable role of epidemiology, alternatively she argues that quantifying and predicting disease incidence is limited in its ability to describe the patterns how and why (ill)health exist. Keeping this in mind allowed my analysis to be cognisant of the frequency in which themes were repeated whilst untangling the connections within the stories. Emerson et al. reminds us to also see the narrative as a complete text and to consider “all the possible reasons for the text having the form and function that it does” (1995, p30).

Once applied to the narratives, the heuristic highlighted many themes worthy of exploring alongside the existing literature. This process allowed me to get closer to the material, but
was still short in terms of inclusion within a syndemic framework. By delving deeper into the key themes contained in the life stories I was able to untangle characteristics that could eventually be considered as synergistic variables in the health experiences of Cook Islanders. Once again, the research and analysis process took on an iterative form as I moved between nuanced accounts and coded examples.

Syndemic frameworks have gained momentum over the last decade. The theory arises from an advocacy for multidisciplinary approaches and holistic thinking and as such, syndemic frameworks can be suitably applied across disciplines. By abandoning prescriptive and reductive methods on health and development, syndemic frameworks offer the opportunity to explore data from different angles. This also offers a rather confusing set of possibilities to be included in the framework. Dealing with interactions between biological, political, social and economic variables forces you to reconsider the interactions in health which you believed to be of most significance. Relying so heavily on intuition can throw up significant research anxiety. An ‘off the shelf’, one-size-fits-all framework may have been easier but it would not have been able to cope with the contingent and complex nature of the data, particularly the force of the transnational social field. Importantly, syndemic frameworks allow researchers to pay attention to the complexity of the data within one population and research design whilst keeping in the mind the hidden or not obvious mechanisms in operation. For example, in this study, the literature makes reference to the role of Vitamin D deficiency as a factor for both TB and diabetes, however, because this was not sensed or expressed during my research by participants it has not been included in this framework. This does not denote the significance of Vitamin D, it simply reflects the nature of the research design.

**Conceptualising the syndemic**

Conceptualising the syndemic and the interactions at play was another important component of the analysis. The conceptualisation of the syndemic began by drawing out the significant pathways of interactions for Cook Islanders with TB and diabetes which had been revealed during the transcription phase of the research. In doing so I discovered that a set of effects and mechanisms were evident in the personal accounts of Cook Islanders living with diabetes and TB. Whilst dealing with these variables a conceptual grid emerged. When this was drafted as an illustration I could see that each effect and mechanism related
to each other. Visually there appeared to be a dense, contingent network of interacting factors. The process of conceptualising the syndemic also hinted at the significance of causality and the direction of the relationships. The dimension of causality within the syndemic indicated that specific interactions corresponded with certain events in the participants’ lives. When working through the pattern that the conceptualisation presented, it was also apparent that the content of some of the ties between TB and diabetes were more significant than others.

In the previous chapters I have argued that a syndemic framework can address the contextual historical, political, economic and social layers of this research. The grid of syndemic connections in Figure 8 is used to explore the idea that a TB and diabetes syndemic exists within the Cook Islands population, which is characteristically transnational. This stage of analysis was driven by the engaging process of moving in between the transcribed interviews from participants and the existing literature on TB, diabetes and harmful social conditions. To begin to take into account the multiple dimensions of a possible TB and diabetes syndemic I conceptualised a grid of variables which I believed were contributing to the health histories and disease experiences of the research participants. This provided an important platform for contextualising the conditions which create, and potentially sustain, the TB and diabetes syndemic. I was guided by the suggestion of Kasl and Berkman to “pay more attention to the process itself [health habits, environmental exposure] so that we may understand the paths that lead to the changes in risk factors” (1983, p.86). This preliminary analysis unpacks the different configurations of health and social conditions which structure the simultaneous threats of TB and diabetes for the Cook Islands population. As Reitmanova and Gustapson argue:

To think syndemically about infectious disease means unravelling the biological, social and historical connections which shape the distribution of infections over space and time (2011, p.405).

This component of the syndemic analysis signals the unravelling or unpacking of the research data and how I engaged with the interview content and my research observations. In a similar manner to the syndemic research conducted by Gassman et al. (2012), the grid is organised along the lines of both the research data and the existing literature on the topic of the TB and diabetes interaction. This allows the syndemic analysis to continue along a path that recognises while the material at hand represents certain connections,
other significant relationships may also exist. Whilst chapter three focused upon the literature pertaining to the possible external and internal biological connections that surround the Cook Islands’ TB and diabetes syndemic, this chapter highlights the synergistic working of this secondary material with multiple pathways and mechanisms within the research data. As mentioned previously, the grid was significant because it was an intuitive response to needing to organise and understand the data collected. I believe that this allowed the dense text to be dismantled into a revealing set of connections.

The TB, diabetes and transnationalism syndemic

The development of the syndemic grid proved to be a necessary step in exploring and interrogating the content of these connections. In a similar manner to Herrick et al., a set of “predictor variables”\(^{21}\) were identified as a way to “summarise a range of adverse conditions and events through the participants’ life course” (2013, p.79). In order to move beyond providing a high level summary of the contributing determinants involved in Cook Islanders TB and diabetes it is necessary to consider the relationships between the variables. Instead of linear pathways of relationships, each variable was assessed in terms of interactive influence in multiple directions. In this way, a complex ‘big picture’ of the syndemic began to emerge.

The repeated patterns and density of the relationships was interpreted as confirmation of the syndemic existing within the Cook Islands population. Where relationships appeared particularly dense it provided a schema for prioritising the underlying patterns and meanings of that particular relationship. The main contribution at this stage of the analysis was the obvious influence transnationalism had on the different dimensions of participants’ health experiences. Transnationalism appeared significant across the range of variables and as such it became apparent that for Cook Islanders, the description of the syndemic may more appropriately be the ‘TB, diabetes and transnationalism’ syndemic. The naming of the syndemic to include transnationalism became a significant part of my work. The engagement of the research material in the subsequent chapters illustrates the significance

\(^{21}\) It is important to note that these researchers used questionnaires as opposed to in-depth interviewing methods.
of transnationalism as a contextual and mechanistic factor within the Cook Islands syndemic.

In Figure 8, the grid displays the significant variables considered within the syndemic. I worked with each variable and considered the synergistic relationship between the axis and evaluated how this relationship operated within the syndemic. The decision to work with the research material in this way also allowed me to prioritise the order of events that affect people's health. When I worked back through the transcripts with this grid in mind I could begin to delineate the important order of events and conditions which had synergistically exacerbated the participants' experiences of disease.

The literature review and transcription of interviews along with observations signalled 16 potentially harmful factors at play in the Cook Islands TB and diabetes syndemic. As a result, 256 relationships have been considered through the process of organising interview narratives and literature. During the process, all of the relationships were considered by interacting with the research material and the relevant literature. A few of the important relationships have been highlighted via notation. These connections become increasingly relevant in the substantive chapters which follow. As such, this grid is an illustration of the analytical process which came to highlight specific relationships considered in later parts of the thesis. It is important to note that these connections are highlighted to illustrate my working and that other significant relationships are also considered. Chapters six and seven are the product of this analysis and demonstrate the interrogation of notably strong relationships in the context of Cook Islanders. To provide continuity with existing research and to provide a benchmark for the subsequent analysis, similar categories were used to those in the literature (Gassman et al. 2012). This design thus allowed comparisons of the importance of these relationships between this study and the literature. A continual process of cross referencing and reconceptualisation has occurred during this process, which I propose contributes to the overall rigour of the research. The design of the grid, which has been refined over a year, has provided a tool for organising the narrative

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22 It is important to note that relationships between TB and diabetes which are found in the literature such as vitamin D and helminths were not accessible through the interviews and have therefore been omitted from the framework.
material, a form of validation against existing literature and reflexive engagement with the theory of syndemics.
Figure 8: Conceptualisation of the syndemic
In the next chapter, five case studies are used to bring to life the complexity and multi-dimensional elements of the TB, transnationalism and diabetes syndemic over time and across space. Each of the stories speaks to the most significant relationships situated within the dense network of the grid. This represents the second stage of research data scaffolding, where stories are used to expand the grid in this chapter within the disease realities of Cook Islanders. The chapter also positions syndemics theory within the contextual layers of the research by demonstrating the range of experiences across the transnational field. The case studies illustrate the significant demonstrable interactions which are later substantiated with narrative analysis.

Summary

The research tools used to collect, analyse and communicate the data in this study moved between places, disciplines, and qualitative and quantitative modes and took shape over a series of years. During the process of this research, different tools were used to understand the Cook Islands population, diseases, transnational social fields and syndemic theory more fully. Moreover, dovetailing these key strands of the study was an iterative process. The weaving of these methodological strands, facilitated by listening carefully to people’s accounts and observing the transnational and health seeking behaviours of Cook Islanders, occurred simultaneously with the preliminary analysis. Reflection upon the methodology used in this study features throughout this thesis. The next chapter sketches my interpretation of a syndemic framework in light of the material collected.
CHAPTER FIVE

Stories and syndemics

Travelling between islands or between countries in search of health services has become a commonplace practice for Cook Islanders. Whilst travel may not be a preferred option for people, it is the only option if the services cannot be provided in their place of residence. At times, travel for health services may be individual; however, among the participants of this research, it is not only the person seeking health services who moves, but often their partners and families as well. For others, travel for health services is a preferred option, because expectations of services have been raised from previous engagements with the health services, confidentiality is important, or family members to assist with recovery reside in other places. In this way, the long history of Cook Islanders within the New Zealand health system has altered health-related decisions and experiences. What is distinctive in the Cook Islands case is that this occurs across national boundaries, and the fabric which weaves together all the functions of a health system stretches across a vast geographical space. Similar relationships also exist for people from the Freely Associated states of Tokelau and Niue where medical practitioners, health promotional activities, medical equipment, diagnostic facilities, people and whole families also transcend island and nation boundaries. Movement across transnational social fields are not seamless. This research throws light on the expectations and experiences that Cook Islanders have of their own health and the overlapping health systems.

In this chapter, the conceptual grid presented in the previous chapter will be illuminated by “disentangling the interconnecting health problems” (Herrick et al. 2013, p.84) of key research participants. The syndemic connections operating on a personal level are untangled and presented as illustrated case studies (pictograms) for five of the participants. These case studies are purposively evocative. They stretch our understanding of how health research can be framed to illustrate the synergistic influences on Cook Islanders’ health. In some of these case studies, the leveraging of transnational ties between New Zealand and the Cook Islands is demonstrated positively, whilst in other case studies, the mobility appears as a negative influence on health. The case studies also demonstrate that even though TB case numbers are low in the Cook Islands population the threat of latent TB
and diabetes alongside socio-economic and cultural factors signifies that even small numbers of cases are important. As Lawson argues:

Migrant stories can reveal the empirical disjuncture between expectations of migration, produced through dominant and pervasive discourses of modernization, and the actual experiences of migrants. Their stories illustrate that access to labour markets, state assistance or social networks, are not mere unique individual experiences but, rather, are systematically shaped by social relations of gender, class, ethnicity and migrant status (2000, p.174).

The interwoven and interacting forces at play on a person’s physical body and the complexities of Cook Islanders’ lives present the complex and overlapping socio-political environment of the transnational social field. The case studies as a collection present the diversity and complexity of personal and familial experiences of diseases, harmful social conditions and associated health conditions. Together, the demonstrable factors such as poverty, overcrowding, limited health care access and transnational behaviours are seen to influence these people’s lives over space and time. The illustrated case studies also depict multi-sited ethnographies’ ability to follow the plot of everyday experiences. In particular, as Marcus argues, this methodology provides for “tracing a cultural formation across and within multiple sites of activity... designed around chains, paths, threads, conjunctions or juxtapositions of locations” (1995, p.96).

I believe the interaction of these factors become highly visible in the following pictures. The chains of events that link people to places and disease experiences are elucidated. The case studies demonstrate that for Cook Islanders, holistic awareness of health issues is necessary. Part of this holistic awareness is recognising that health service access occurs at multiple scales, including inter-island (translocal) and transnational experiences. In this way, the public responses to Cook Islanders’ health are stretched across island and national boundaries. To navigate these health pathways Cook Islanders employ a range of health strategies over an array of different institutions. This chapter attempts to capture the multiple dimensions of change occurring for the participants within a transnational context. This builds upon an understanding of what Hannerz (1996) refers to as conceptualisation and description of connections. The conceptualisations of syndemic connections in this chapter relate specifically to the experiences of Cook Islanders. With my own conceptualisation of this syndemic in mind, these case studies emerged as poignantly
illustrating not only the syndemic forces within their own experiences but also echoing the experiences of others. These case studies also connect with people who read them in a particular way which spurs on thinking about similar experiences or stories in other places.

The five illustrated case studies are presented as a collection and the corresponding analysis of each case study is located in the second half of the chapter. Two of the case studies in this chapter bring forward the issue of kidney disease and renal failure as an associated condition of diabetes. Including these cases within this collection interrogates assumptions that Cook Islanders can freely move between the Cook Islands and New Zealand and raises questions regarding national responses to the health services. For these people, their transnational livelihoods and relationships have been altered by a health outcome.
JOHN LINDSAY is a prominent Cook Islands musician who has lived in many places.

From 1989 – 2003 John lived in the Hayman Islands, Australia. In 2003 he remembered feeling very tired and needing to sleep a lot.

Later that year John decided to return to Rarotonga to live. John wasn’t home for long before he was diagnosed with Type 2 diabetes.
In 2004, John went to the hospital in Rarotonga because he was feeling dizzy. The doctors discovered that his kidneys were failing.

The next day he was transferred to Auckland for treatment and fitted with a peritoneal dialysis so that he could travel back to Rarotonga.

He used the peritoneal dialysis successfully for a year, until he got an infection from dialysing on his verandah alongside a dog.
Once again John was referred from Rarotonga hospital to Auckland hospital where he was fitted with Haemodialysis. This restricted John’s travel to places with dialysis facilities or for journeys less than three days long.

Since 2004, John has managed to travel to Australia using both private and public dialysis facilities.

In 2011, John was diagnosed with a reactivated form of Pulmonary TB.
The two adults and one child who live with John were contact traced and all responded negatively to the TB skin test.

John’s TB treatment lasted six months, during which time he was removed from the kidney transplant list.

Since this time, John has returned to Rarotonga for visits of no longer than three days. Until a kidney transplant or a dialysis unit is established in Rarotonga, this is his only option.
This is the story of how Ta’i was diagnosed with Type 2 diabetes. Sometime in 2000, Ta’i got a splinter in his finger from gardening. He was 50 at the time.

A few days later Ta’i went to the main hospital in Rarotonga to receive treatment for the splinter in his finger because it had become infected. At this time he was also tested for Type 2 Diabetes. The test was positive and he has been on treatment for Type 2 Diabetes ever since.

Unfortunately, the treatment for his finger did not work. Two days later the doctors amputated the finger outside the operating theatre in the corridor without general anaesthetic.
**PAPA SAUL** was born in 1969.

In 2000 he was diagnosed with Type 2 diabetes.

In 2007 he was admitted to Aituaki hospital for two weeks because he had a persistent cough.

The doctor suspected he had lung cancer.

Papa Saul was placed in a general ward.

A sputum sample was collected in Aitutaki and sent to Rarotonga for reading.
A few days later he was told he had TB and that he would be transferred to Rarotonga for treatment. Papa Saul flew to Rarotonga unaccompanied on a general passenger plane with no mask.

In Rarotonga he was in an isolated ward for three months receiving treatment. He remained in Rarotonga for further treatment for another three months.

Contact tracing was performed with his family in Aitutaki. There were no other confirmed cases.
In 1979 **TU** was working in Wellington with his brother. During this time, Tu’s brother was diagnosed with TB.

His brother died three years later from associated complications because of his Type 2 diabetes. Tu travelled to Australia and back to Rarotonga during the early 80s.

In 1986 he arrived in Auckland with his wife and 18 month old son who had leukaemia.
His son was initially treated in Auckland but then Tu requested a transfer to Christchurch to be closer to family.

Once they were settled in Christchurch, Tu returned to Rarotonga for work for a month before returning to Christchurch for the arrival of his new baby.

He stayed for two weeks then returned to Rarotonga for a short period to leave his job and return to Christchurch more permanently. A few months later they moved to Wellington and then on to Porirua.
In the late 1990s Tu was diagnosed with Type 2 diabetes.

Because he did not comply with medication, Tu now has renal failure.

Tu has a peritoneal dialysis and performs his own treatment at home.

He chose this form of treatment in the hope that he can return to Rarotonga for short periods of time in the future.
Rangi’s mother moved to Auckland in 2004 for stroke rehabilitation. A year later she experienced renal failure as a result of her Type 2 diabetes.

In December 2006 Rangi’s mother was admitted into hospital and a chest x-ray revealed she had pulmonary TB.

She died on Christmas Eve in 2006. Rangi’s mother had been living in a two bedroom state house with five other adults and seven children.
When the Public Health Nurse arrived to perform the contact tracing she discovered they were preparing to take the body back to Rarotonga for burial.

Contact tracing was performed with everyone but Rangi’s father because he was leaving for Rarotonga before the Mantoux test could be read. This concerned the nurse because he appeared to have some symptoms of TB.

Rangi, his brother and his niece accompanied their father and the body back to Rarotonga.
Meanwhile those in the house needing treatment for latent and active TB received treatment from the Public Health Nurse. Three adults received treatment for latent TB and the youngest grandchild received DOTs for active TB for six months.

In Rarotonga, the funeral was held and Rangi, his brother and his niece travelled back to Auckland.

Rangi’s father stayed in Rarotonga for one year. Eventually, Rangi’s brother, sister in law and niece and nephews travelled to Rarotonga to accompany Rangi’s father back to Auckland.
During this year, another baby was born and the treatments were completed.

Rangi’s father was tested for TB in 2008 along with those who had travelled to Rarotonga to bring him back to Auckland.

The children’s TB statuses had changed, and Rangi’s father had active pulmonary TB.

Rangi’s father was admitted to Auckland Hospital for his treatment. The Chief Medical Officer of the Auckland District Health Board wrote to the Cook Islands Ministry of Health urging contract tracing to be carried out with the family in Rarotonga.
While Rangi’s father was in hospital, the PHN arranged for the two families to be housed separately to relieve the overcrowding.

Rangi’s father died in 2009. Once again Rangi and his brother accompanied the body back to Rarotonga.

The risk of TB surrounded this family from many directions. Historical and contemporary exposure to TB interacted with type 2 diabetes, population mobility, household overcrowding and poverty to produce a painful experience of TB that lasted five years.
Case study 1: John Lindsay

John Lindsay\textsuperscript{23} was introduced to me through an Auckland District Health Board (ADHB) PHN who works in the suburb of Avondale. John Lindsay had been receiving DOTs for TBD from this nurse over several months during 2011. The PHN had told me about John, saying that he would make an interesting participant because of his health problems and his high status position within Cook Islands society. John maintains this position because he is a well-known and respected Cook Islands musician. Despite his TB, diabetes and kidney failure he continued to work and perform internationally with other Pacific musicians when he was well enough. During his period of receiving DOTs, he was still spending time in music studios and recording pieces when he felt well.

This case speaks to wider themes uncovered during participant interviews. John, like other male participants, believes that he was probably diabetic for some time before being diagnosed. John could list a range of symptoms he was experiencing whilst living in the Hayman Islands. However, he did not seek treatment until he returned to Rarotonga. At that time, John’s diagnosis experience was described to me as the “beginning of my nightmare”. This nightmare quickly progressed, because in less than a year, John was also diagnosed with kidney failure, an event which resulted in an organised referral to Auckland hospital for treatment and the fitting of a peritoneal dialysis.\textsuperscript{24} The decision to use a peritoneal was made so that he was not dependent upon haemodialysis facilities and could travel back to Rarotonga, as long as he could transport his equipment. This decision illustrates a particular health strategy employed to allow for John’s continued participation in a Cook Islands transnational livelihood.

The case study also tells us of the risks John took whilst using the peritoneal, despite being told to always dialyse in a hygienic place indoors. We spoke about this particular risky scenario and John connected many other examples of his conscious defiance of medical advice; not attending a clinic earlier to seek diabetes testing, not taking medications and

\begin{footnotes}
\footnotetext[23]{John Lindsay requested that his real name be used in this study. He felt very strongly that his was participation an opportunity to tell his story and his struggles of not being able to return to the Cook Islands.}
\footnotetext[24]{Peritoneal dialysis is a treatment for chronic kidney disease. It involves having a permanent tube in the patient’s stomach through which fluid enters the body to assist in flushing waste from the blood.}
\end{footnotes}
not adhering to the dialysis schedule. It was not until John experienced a kidney infection and was once again transferred to Auckland to be fitted with a dialysis that he began to accept his diabetes and renal failure. What John did not realise is that his lack of compliance with diabetes and peritoneal dialysis would severely impact his ability to spend longer periods of time in Rarotonga in the future. The fact that there is no access to dialysis in Rarotonga plays constantly on John’s mind because he can only visit Rarotonga for very short periods of time. Moreover, it has meant that John has had to reconsider his retirement plans. John, like many other Cook Islanders, believed that hard work overseas would one day lead to comfortable retirement back in the Cook Islands. A kidney transplant is presently the only opportunity for John to return home for longer periods of time. Even with a kidney transplant a permanent form of residency is unlikely in Rarotonga, given the fragility of transplant patient’s immune systems and the contraindications of anti-rejection drugs.

John was high up on the transplant list but was then diagnosed with reactivated TB. John was removed from this list until his six months of DOTs was completed, and then he began the long wait from the bottom of the list again. In this way, the interaction between TB and diabetes affected John’s life beyond the biological and affected his position politically on the transplant list.

Despite this, part of the process of accepting his condition led John to investigate new ways that his transnational behaviours and career could progress despite his reliance on dialysis facilitates in New Zealand. John has successfully visited family and performed in Australia because he was able to gain information on how New Zealand citizenship related to dialysis in Australia. He has both paid to use private dialysis facilities and been able to use public services because of his New Zealand citizenship. The case study illustrates that John Lindsay could strategically access services and continue working and in doing so, highlights the positive consequences of his New Zealand citizenship attaching him to health services in different locations.

The decision to include John’s story upfront in this series is to signal key syndemic connections. First, the risk of reactivated latent TB loomed in the background of John’s life and was experienced after the diagnosis of diabetes and renal failure. Second, John’s
transnational behaviours were not only a source of livelihood but also a perceived barrier to him not seeking medical attention. Transnational health access is also illuminated in this story alongside the reality that his own mobility has been reduced as a result of his dialysis. In addition to these dimensions of John’s story, through the multiple in-depth health interviews and observations in his home, it was clear that the socio-economic disadvantages which feature in the subsequent case studies were absent in the case of John. There is a positive aspect to this case study which speaks to the ability of Cook Islanders to continue to live comfortable lives on renal dialysis if there are enough financial resources, education and employment opportunities for them to do so.

Case study 2: Ta’i

The nutritionist at the Cook Islands Ministry of Health encouraged me to arrange an interview with Ta’i. Although she didn’t give reasons as to why he would make an interesting participant, her insistence registered a high level of curiosity about Ta’i. When I arrived to meet him, I experienced my own socially constructed stereotype of Cook Islands diabetics unravelling. Ta’i was thin, fit and active in appearance. I had not realised that I had succumbed to popular ideas of diabetes, but my surprise when I met Ta’i demonstrated that I had indeed began to view people with diabetes as synonymously being obese (see chapter seven). It was made apparent to me that I had been making certain assumptions as to what the diabetic individual ought to be (Goffman 1970). We spent over one hour together in the office of his workplace, and our conversation began, like the other participants, with his health history. His story began ten years prior when he had been diagnosed with diabetes in his 50s.

The significant events in his health history which led to diagnosis were repeated in other interviews. For male participants, interaction with health services for diabetes diagnosis was more likely an outcome of visiting a hospital for an injury related to sport or gardening (see chapter six). Although Ta’i believes that both his sister and his mother died of diabetes, his awareness of the seriousness of his diagnosis did not occur until he researched his condition:

Ta’i: Well at the time there was no shock, there was nothing, but after that being able to access information and then sort of thought oh just as well I had gone to the doctor early otherwise I would have
lost an arm, and then you read about other people suffering from things, so it was scary. In the above quote Ta’i introduces the ideas of ‘suffering’ and being ‘scared’. From this point, he proceeds to a description of his corresponding emotions when his finger amputated:

Ta’i: The doctor came and looked at it and said ‘oh yes, you need to get it chopped’. Instead of saying, ‘oh no I’m sorry, it’s poisoned, it will cause gangrene if you don’t have it chopped off, you need to go into the theatre and get it cut off… So they had to put medication on it to clean it up and then they pushed me towards the theatre and left me outside for a while and did the operation outside the theatre.
Evelyn: Why?
Ta’i: I don’t know, they numbed it.
Evelyn: So you were awake in the corridor?
Ta’i: Yes! And I thought to myself this is the way they treat you! This was the first (operation) time, so it was a shock.

The narrative above signals an important dimension to the interviews I had with participants about TB and diabetes. Their past experiences of treatment in the hospitals or clinics were reasons for either not seeking treatment or seeking treatment elsewhere:

Ta’i: Yes a lot of them because of previous things they decide to go overseas, even pregnancies, some girls are frightened and take off… Sometimes through experience and some through hearsay ‘oh you know, don’t go there because it’s, I could have gone around saying bloomin’ doctor left me in the corridor and chopped my finger, that would cause quite a lot of people, and you get stories and rumours that the doctor didn’t do or the nurses (didn’t do) and so people take off.

During the interview with Ta’i I began to question my own assumptions of what diabetes patients ‘look like’, variable paths to diagnosis, and treatment within the health systems. The story of Ta’i, his diabetes, and amputation vividly displays the emotions of suffering and fear that were felt by many of the participants. During the interview Ta’i appeared to appreciate the opportunity to share his experiences with a person outside of the close knit Rarotongan community. Furthermore, Ta’i was able to connect his own emotions to the experiences of others in way that contextualised with strategies to ‘take off’ and seek health care elsewhere. It was during this interview that I began to more fully understand the Cook
Case study 3: Papa Saul

The third case study in this series illustrates the interisland movements of patients and health services in the Cook Islands. In particular this case study illustrates Papa Saul’s experiences of TBD between his home island of Aitutaki and Rarotonga. I was introduced to Papa Saul through the PHN in Aitutaki. We spent one afternoon together talking about his TB and his diabetes. In the case of John Lindsay, his TB was auxiliary to his diabetes and renal failure. In this case study, Papa Saul’s experience of TB was the lead story in the interview because of his time spent away in isolation in Rarotonga. He told me this was “just like a jail”.

Papa Saul vividly retold key events about his experience of being diagnosed and treated for TB. The story began with Papa Saul explaining that he was already very ill when he arrived at the hospital in Aitutaki. At first the doctor suspected that he had lung cancer because he had previously been a heavy smoker. The diagnostic equipment necessary in the case of cancer is not available in Aitutaki, so onward travel to Rarotonga was arranged, and if necessary, on to New Zealand for treatment. During this process, Papa Saul was placed in a general ward. Aitutaki had not had an active TB case for some time; however, a sputum sample was collected and sent to Rarotonga as part of standard protocol. The test was indeed positive and he was transferred to Rarotonga for treatment on-board a passenger plane. An essential part of the protocol to wear a mask during this one hour trip was forgotten, and Papa Saul vividly remembers the doctor’s shock when he arrived at Rarotonga hospital without a mask. The increased risk of TB in overcrowding houses is well established, however in this case study two other key events point to possible risks of active transmission. Protocols surrounding suspected TB cases need to strengthen in the Cook Islands to minimise active transmission risks in hospital wards and on-board passenger planes. Overall this case study is intended to convey the complexities involved in the diagnosis and treatment of patients in between islands. It also signals the isolation and

25 It is important to note that beyond the misconception among Cook Islanders that life in New Zealand is better for health, molecular fingerprinting technology also indicates that TBD is more likely to be a reactivation of latent TB (Sexton et al. 2008) and higher levels of diabetes among migrant communities are due to nutritional transitions and urbanised habits (Candib 2007).
loneliness that some patients experience when they are distanced from their home for long periods of treatment.

**Case study 4: Tu**

The next case study in this series adds to the complexity of transnationalism, TB and diabetes. Aside from Tu’s history of caring for a son with leukaemia, his brother dying of diabetes and his own diabetes and renal failure, another striking feature of this case study was Tu’s decreasing employment opportunities because of the health of his son and later in life, his own. Tu had travelled earlier in his life and experienced life in New Zealand and Australia. In his thirties he decided to stay in the Cook Islands, held a position of status within the government and earned a stable income. However, the health of his son was the first obstacle to maintaining this career and was the significant event that placed Tu in New Zealand more permanently. Tu’s life changed dramatically when he moved to New Zealand from Rarotonga. He had once been employed as a government official and had secure housing. On moving to New Zealand, he found employment in door to door sales and had to rely on Housing New Zealand accommodation. Nevertheless, Tu and his wife raised a large family. Once the children were settled in their secondary education Tu decided to study for a qualification in social welfare. He was mid-way through the degree when his kidneys failed and has since been unable to return to work or study. Tu’s wife is now the main income earner in the family and juggles the childcare of her grandchildren during the day with a cleaning job in Wellington at night.

Tu’s story also highlights movement to different regions of New Zealand and between the North and South islands. Tu’s decision to move to Christchurch illustrates that proximity to family is important during events affect health. It is often assumed that such family care can be provided in Auckland, however, for some Cook Islanders, the transnational social field has concentrations of people in other places. Although Cook Islanders can use their New Zealand citizenship to access medical services in New Zealand, support mechanisms in the form of welfare or family support can be extremely difficult to organise for some families.

Like John Lindsay, Tu had been defiant towards doctors and retold several stories of taking risks by not taking his diabetes medication (see chapter six for more details on how this
appears to be a male disposition). He attributes this to defiance as why his kidneys failed. The decision to have the peritoneal fitting was based on his desire to travel to Rarotonga for short periods of time. However, unlike John, who has some means to travel freely between New Zealand, the Cook Islands and Australia, Tu will have to save considerable amounts from his limited resources to pay for airfares and for shipping the dialysis fluid. During the interviews I had with Tu I came to realise that for some Cook Islanders, health is the only reason they arrive in New Zealand and may also be the only reason they have to stay:

Tu: My dream is one day I will go back to Rarotonga. I know it’s hard (because of dialysis). The special reason why I wanted to go on peritoneal is because my hope is one day I will go back to Rarotonga. If I go on daemo(dialysis) I can’t go back. The most you can stay is three days. Whereas with peritoneal, I can stay there as long as I like. The only issue would be how I could pay for my equipment to go to Rarotonga. See we are not talking about one or two bags, it’s about 35 bags. That’s my monthly supply before the next load gets in (points to corner filled with large boxes containing dialysis fluid).

**Case study 5: Rangi**

The last case study in the series highlights the serious socially, politically and biologically demonstrable connections that surround not only one person but multiple families. Whilst the illustrated case study is told via Rangi, it needs to be mentioned that one out of the three interviews with Rangi also involved his wife. The decision to narrate the story through Rangi rests with the initial event of his mother’s death as the significant entry point to the story. Rangi and his wife were introduced to me through a PHN who worked in Glen Innes, Auckland. The PHN had worked with the family for over a year, and although they were not undergoing treatment at the time of interviewing, the nurse thought that they might be interested in participating. Rangi and his wife were eager to share their stories with me during several interviews carried out over a year. Towards the end of the interviewing it became clear that the interview process had helped their understanding of the chain of events that had affected their family.

In Rangi’s case study, the socio-biological relationship between diabetes and TB is clearly illustrated. What is also made clear is the potential health promoting and health demoting role that transnational behaviours can play. Health access was initially sought by Rangi’s
mother and instigated further mobility from extended family, which in this case also led to household overcrowding. Furthermore, culture, transnationalism and health can be seen to interact as movement for burial complicated the TB diagnosis and also led to the TB statuses of some of the family members changing. Whilst not explicitly illustrated, this story speaks to the vulnerability of children in the case of active transmission of TB. The scene in which this story takes place also conveys the reality of poverty. The entry in my research diary after the first of three visits to the home of Rangi and his family documents their living conditions:

Research diary entry 8 July 2011

It has taken a whole day to write about my meeting with Rangi and his wife. The day I visited it was terribly cold and grey. I haven’t been to Glen Innes in a long time. Driving down the hill into the valley the change from privately owned to government residential housing was obvious. Rangi and his wife live in a four bedroom state house. Upon arriving I noticed how cold the house was. There was no heating. I could hear children. Rangi’s wife apologized for the mess of the house which was both untidy and dirty. I needed to use the bathroom and I had to climb over mountains of empty toilet rolls to get there. It smelled of urine and there was blood on the wall. The bathroom where I washed my hands had an old school lunch strewn all over the floor... The children were not well dressed for the winter. They had cold little black (from dirt) feet. Where was the disconnect? Both the adults were well dressed for the climate, the children were not. The little girl who had had TB only had a T shirt on. She also had itchy skin and was scratching a lot. The children looking cold in the winter really affected me.

The above research diary entry demonstrates my emotional response to the impoverished living conditions of Rangi and his family, particularly the children. The first interview with Rangi and his wife sketched the outline of this family’s experiences of TB while simultaneously raising important issues about the wider social and cultural factors influencing this family’s health experiences. The grim picture of little, black, cold childrens feet stayed with me for some time. Overtime however, these images gave way to new images of the family. The family became more organized as Rangi’s wife returned to study and Rangi himself looked for paid employment. On my last visit I remember a task sheet in a prominent position in the living room allocating household chores to the household members. Although at the time of my first interview TB treatment had stopped, the turmoil the events had produced for this family was still very present in the house.
This case study also signals that some families fall through the gaps of both health systems. The reality is that fractures in the health systems exist in terms of following up on the movements and health of Cook Islanders. There are events in New Zealand and the Cook Islands which could have changed the situation for Rangi. First, whilst not normal protocol, Rangi’s father could have had a chest x-ray to test for TB. This is a procedure that can be read on the same day, thus accelerating his treatment for TB, and reducing subsequent case numbers of TB. Second, correspondence\(^{26}\) between the Auckland District Health Board and the Cook Islands Ministry of Health did not lead to contact tracing being conducted in Rarotonga.

Summary

Herrick et al. (2013) suggests that there needs to be ongoing refinements and testing of syndemic theory so that new understandings of health in marginalised communities can be reached. The complex nature of the participant’s health histories led me to isolate events in specific case studies which illustrate particular dimensions of the Cook Islands TB, diabetes and transnationalism syndemic. These case studies expose the social, biological, cultural and political connections which surround Cook Islanders’ experiences of TB, diabetes and transnationalism. In this way, the syndemic framework has progressed from a methodological orientation and focus on high level findings, towards situating the experiences of the interactive forces at play onto the lived realities of the participants.

These illustrated case studies have allowed a simple grid of interactions to come to life and frame the issue of TB, transnationalism and diabetes. One of the strengths of syndemic frameworks is that it allows research to move between modes of analysis with each stage building upon the complexity of the one before. In combination the case studies have highlighted a set of high level findings which work alongside the syndemic grid in chapter four. Within the stories of the five participants distinctive relationships exist. The transnational social field is seen to exert influence not only the access of health services but also differential migratory experiences and expectations of health care. The case studies from Rarotonga and Aitutaki also signal that health for Cook Islanders exists across many

\(^{26}\) Medical records were sought to confirm this in Auckland. Whilst in Rarotonga, no dates of contact tracing being carried out corresponded with the dates of Rangi’s father travel. Although I could have identified this family for interviewing, I did not so that I could preserve this family’s anonymity.
different settings where there are particular constraints to delivering care. Decreasing social mobility features in the case of Tu as he transcends the transnational social field. For John and Tu, the expectation of retiring in the islands is interrupted because of renal dialysis. Other interactions for TB and diabetes include social and economic hardship which interacts with variables such as nutrition, housing and health service access. The connections and gaps in the health systems and how these are navigated are particularly persuasive in the case of Rangi and his family. The case studies anecdotally begin to paint the picture of how TB and diabetes are situated within the lives of the participants. In some cases, diabetes is located in the background of the health and mobility stories and in other cases it occupies the central position. In the next chapter, the connections between these two diseases and transnationalism are detailed through narrated accounts and significant threads of the syndemics and health and development literature are described. In this chapter, the accounts of the participants portray the additional significant interactions between food, culture, stigma and fear.
CHAPTER SIX

Personal expressions of TB and diabetes

This chapter uses the narrated experiences of the in-depth health interview participants\textsuperscript{27} to convey the complexity of social, cultural, economic and biological interactions at play. The narratives and corresponding analysis are used in this chapter to express the content of ties within the TB, diabetes and transnationalism syndemic. The literature on TB and/or diabetes has provided many empirical studies detailing the interaction between these diseases and overcrowding, poverty, and tobacco smoking (see chapter three). I consider these studies within the relationships that were found to distinctively interact for the Cook Islands population. This chapter focuses upon the patterns and meanings of two key findings. Within the narratives, issues relating to the diagnosis of TB and diabetes, and the relationships with food, nutrition and culture were repeated by participants across all study locations. The underlying influence of stigma weaves through these personal accounts.

This chapter begins by discussing how the physical manifestations of disease relate to diagnostic and treatment behaviours. The event of diagnosis and subsequent treatment behaviours portrays some of the obstacles to Cook Islanders seeking health services. It also signals a key area where the Cook Islands and New Zealand health system could begin to destabilise the links between TB, diabetes and transnationalism by shedding light on the interplay between structural and personal health service access. Second, the role of food, food insecurity and nutrition is discussed with attention placed on the socio-economic and cultural constructions of food. The relationship between food and the body is central to nourishing the body and in the Cook Islands population it is also a significant factor in maintaining cultural and community connections. This section demonstrates that this relationship can be disrupted by health conditions, migration, stigma and the lack of financial resources. Therefore it is argued that the interaction between the body and shifting relationships with food are argued to worsen the negative effects of the syndemic. Third, the pervasive force of stigma experienced by the participants is used to convey the significance of stigma among the participants with diabetes. Stigma, which is strongly

\textsuperscript{27} The participants presented in this chapter feature elsewhere in the thesis and pseudonyms used in this chapter are consistent with those in other chapters. For brief participant profiles refer to Appendix 1.
correlated with health history, cultural perceptions of disease, socio-economic status and feelings of isolation is used to explore the connections between participants' bodies and their relationships with society. As Riessman states:

Collectively, research suggests that when a condition is potentially stigmatising individuals strategically manage information about themselves in interactions. They control what others know about them by selective disclosure or concealment. An invisible and potentially stigmatising attribute can remain hidden; an actor chooses whom to disclose to and when (2000, p.113).

**How diagnosis changes perceptions of the body and ‘health’**

Evelyn: So how have you been? You all good? Healthy?
Solomon: Healthy? What's that [laughs]? 

Nichter suggests that to understand how disease is comprehended in different cultures, we “must appreciate how the body is thought about and ‘sensed’” (2008, p.25). Within this study it became apparent that how people sensed their bodies altered depending upon diagnosis, previous family histories and access to health services. In this way, I uncovered numerous examples of how “ideas about how the body functions are dynamic” (Nichter 2008, p.37). Although a person’s construction of their health and that of their family is subject to emotional, cultural and political experiences; I began interviews with questions relating to the kinds of physical and bodily manifestations of disease(s). However, as Solomon suggests in the quote above, beginning interviews with physical understandings of health can also uncover alternative subjective and experiential ideas of health (Nichter 2008).

It became clear that people’s physical experiences of TB and/or diabetes began with diagnosis. Previously, participants reported not feeling well and could accurately list a range of symptoms that would connect their bodily experiences with either or both of these diseases. The sensory understanding of participant’s bodies was always clearly conveyed using a mixture of biomedical explanations and health analogies familiar within their families. For example, with regards to TB, people would say that they had a cough that brought up ‘snot’ (phlegm, sputum), or in the case of diabetes that they had trouble ‘going mimi’ (urinating). Participants appeared at ease with this line of enquiry and I attributed this to being exposed to western medical models over time.
Before proceeding to descriptive accounts of diagnosis, the gendered characteristics of both my case studies, narratives included in this section, and diagnosis, characteristics which feature below need further discussion. The case studies which featured in the previous chapter and the majority of the accounts included in this section are mostly from male participants. Whilst this does not reflect a disproportionate number of male participants in my interview group, it does reflect that where multiple interviews were possible, these were usually with men (with the exception of Anabelle). This bias is attributed to the fact that serious conditions associated with diabetes and a family history of TB and diabetes appeared more common among the male participants. Within the interviews, I also discovered that a delay in seeking diagnosis was more common among men. This repeated scenario warranted further exploration as to why this pattern exists and influenced my selection for multiple interviews with particular participants. This pattern of delayed diagnosis among male Cook Islanders is discussed in the section below, and signals the opportunities within syndemic studies to bring to light the gendered characteristics of health issues (see chapter eight).

Although men were able to retell the sensory experience of realising they were unwell, their health histories revealed that this occurred up to several months or even years before seeking medical attention. The hesitancy to use the health services in each of the study locations existed despite participants recognising that the symptoms were most likely of a serious nature. Macpherson and Macpherson (1990) provide some clues to the issue of Cook Islanders avoiding the diagnosis of diabetes despite suspecting that this may be the cause of the health conditions they were experiencing. According to these authors, Samoan self-diagnosis can be used because it is initially quicker, more convenient and cheaper and that self-diagnosis may “spare him or her the embarrassment of public disclosure” (p.190). Avoiding embarrassment also signals the connection between diagnosis and strategies to conceal the health issues being experienced by the participants (Riessman 2000).

I also found that among the Cook Islands male interview participants that denial and fear of diagnosis, combined with expected judgement from hospital clinicians and family members strongly influenced delays in diagnosis. The pattern of pre-diagnosis denial among the male participants was attributed to witnessing the struggles other family members had
experienced with diabetes, and the stigma experienced by those who suffered from TB. In the case of diabetes, men were often diagnosed after they had attended a clinic for an injury from work, gardening or sport. In the case of Papa Saul, he delayed seeking medical attention for his cough because he suspected he had lung cancer. Fortunately, the health services in the Cook Islands have responded to gendered delays in accessing medical services by carrying out routine checks of blood pressure, blood sugar levels and weight measurement during treatments for spontaneous sports related injuries or surface injuries for men. Men’s Health Clinics also started to operate in a clinic in Tupapa, Rarotonga as a response to observed delays in seeking medical attention amongst Cook Islands males. These clinics operate beyond the normal clinic hours to allow those who work to attend. The clinics are operated by an all-male team of health professionals (including male nurses). These men’s clinics have also temporarily travelled to the outer islands in the Cook Islands to provide men in the outer islands with information and treatment relating to NCDs, prostate cancer and erectile issues.

Figure 9: Signage for Men’s Health Clinic in Tupapa, Rarotonga
The narratives of Ta’i (see Case study 2) and Tupou (below) illustrate a scenario where symptoms experienced were ignored until an injury placed the men in contact with health services.  

Evelyn: Did they think you had it for some time when they diagnosed it?  
Ta’i: Yes, but it was an accident that I had, I hurt my finger because I was weeding and a splint got stuck into it and my whole hand swelled up so I didn’t realize what it was until I went to the doctor. The doctor said I’d got diabetes... I remember, as I said I didn’t know I had it, there was sore legs all the time and I was weak, wanting sweet stuff all the time and drinking practically morning, noon and night, not water or anything like that, I was thirsty most of the time. So after that I felt a bit better and I couldn’t do a lot of work around the home without getting too tired and then I could sleep properly.  

Tupou: That’s when I found out that it started off like, ah I had a, cut on my foot, but it was taking a long time to heal. It took a long time to get healed and then (I thought) ah I hate this, it’s awkward, so I went up to the hospital, he said oh, I need to do some checks on you, and they took me through the tests and then, they diagnosed me and my diabetic was increasing. Yeah it was that, that incident made me, that time I was in hospital, I’m, I’m a diabetic. Evelyn: Did you have any symptoms before that? Just the cut on the foot?  
Tupou: It was the cut on the foot. It took a long time to get healed. And, apart from other symptoms like headache and that I had some flu symptom or whatever. But it was this cut on the foot that made me think again because it took a long time... It was at that time he took me through they ah for ah, the for ah for the diabetic, the blood test and all that, ok, so it was through that, that I am diabetic... 

For Ta’i and Tupou there was a range of “mundane” (Nichter 2008) health issues occurring. These included being thirsty, needing to go to the toilet more frequently, craving sugar, feeling weak, simple injuries to the skin not healing, headaches and flu like symptoms. In isolation, one of these symptoms may not have produced health care seeking behaviour, but the combination of these symptoms meant that the participants started to question their bodily function. Although, for both of these participants, they arrived expecting a topical treatment for a surface injury, the proceeding diagnosis was shocking but not

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28 It is expected that because of women’s reproductive health, that more frequent contact with the health services may influence earlier diagnosis of medical conditions.
unsurprising. Ta’i and Tupou, like other participants, could speak freely about the way in which in hindsight, they should have sought earlier medical care. The quotes signal what Mendenhall argues should be central to understanding diabetes in a syndemic framework. For example:

A chronic illness such as diabetes transforms and disrupts the everyday lived experiences of people who suffer from it. As such tales about living with a chronic illness and making sense of its causes are central to diabetes narratives (2012, p.35).

The accuracy with which participants spoke about their symptoms prior to being diagnosed signalled the need to explore more thoroughly the personal and systematic barriers which were obstructing a timely diagnosis. In all research settings, the medical service is equipped to test and diagnose diabetes, therefore I began to suspect that ignoring these symptoms may well have been a conscious health-related decision, or put more simply, a strategy to conceal the possibility of having diabetes. For example, within the account above, the participant reveals the jolting reality that he is now “a diabetic”. The vivid moment in which participants could convey their diagnosis and the significant weight attributed to becoming a ‘diabetic’ suggests that one of the reasons could be fear of diagnosis itself. Hay in her research of TB experiences among patients in Auckland also uncovered evidence that delay in diagnosis and apprehension is tied to a “fear of what might be found” (2009, p.71). After diagnosis, the participants began to embed different meanings into health and disease. It was frequently repeated that participants who had either or both TB and diabetes believed that their bodies and their wider social lives had changed. Aside from fear of what may be found, there also appeared to be fear of what Goffman refers to as a “process of social rejection” (1970). Understanding the exact way in which their lives had changed was more easily expressed in relation to social experiences, including stigma, embarrassment at social events and family relationships. Diagnosis for Cook Islanders appears to both identify a disease and/or health condition while at the same time altering their relationship with their body and the wider community (see section below on how this is manifest through processes of stigma).

The different experiences of accessing the health services over time also played a significant role, causing delay. In the Cook Islands, medical doctors are well respected and have a high status in society, predominantly they are also men. Medical doctors often progress into
positions of political leadership and hold prominent roles in village life. Exchanges with medical service providers for Cook Islanders were described to me as beginning from an unequal power position. This description included the participants being aware of unequal levels of education, service providers having been to university overseas and their inclusion in village, island and national events as an important person. I attributed the socio-cultural and educational differences between doctors and patients to why the participants expressed feeling embarrassed, shy, or scared of being belittled by doctors. Unequal power positions between traditional medical practitioners in Samoa and lay people in Samoa were also found by Macpherson and Macpherson (1990) as a deterrent to seeking treatment. I believe that in the context of Cook Islanders across the transnational social field that this contributed to a delay in seeking medical attention in the first place, and also stymied the participants’ abilities to ask questions relating to their health. This can be interpreted as a particular type of engagement between the participants and the social structure of the health system. While the relationship between participants and doctors appeared among the participants in New Zealand as well; whilst in Rarotonga I talked at length about the position of doctors in society with Mona, a Public Health Nurse. The nurse told me, that doctors were considered “Big People” and that people felt too shy to ask questions and did not want to convey their ignorance. Beyond being hesitant to share the details of their health with doctors because of wider social relationships with these people in the Cook Islands, the participants in both places did not want “to be told off”. In the literature Ong argues that:

> although health providers are well meaning and sympathetic, the pressure to ‘do something’ with patients often means in practice that ‘cultural sensitivity’ is used in a limited, strategic fashion to win patients’ cooperation, facilitate diagnosis and buttress the doctors’ authority, rather than to give equal time or relative biomedical knowledge (1995, p.1248).

When talking to doctors and nurses in both the Cook Islands and New Zealand it was obvious that a well-meaning desire to assist the patient existed, however, the tone and manner, whilst being at times strategically employed to exert authority in the matter of health, actually created a deterrent to seeking diagnosis and adhering to treatment. Thus, the perception participants had of doctors as part of the health systems, obstructed diagnosis and also created a barrier to more fully understanding the importance of
treatment. It should also be noted that because of the personal proximity of doctors and nurses to patients in the Cook Islands a different type of vested interest can also be present. For example, if the person you are treating is your aunt or your nephew, the boundaries between family and professional medical advice is blurred. In an interview with one doctor in Rarotonga he told a scenario of “hunting down” a family member who he knew had not been adhering to his medication and reprimanding him in front of an entire sports club. Because this doctor had worked in New Zealand he understood the ethical dilemmas of this approach, however, he made a wider call that health services needed to be contextualised according to the place and community.

On one occasion I was also told a story about doctors and nurses yelling at diabetes patients. Ta’i (Case study 2) cited this as the key reason why some people did not seek health services for fear of harsh criticism from doctors and nurses. Furthermore, Ta’i believed that the fear of being demoralised is why some patients did not attend clinics to get new supplies of medications.

Ta’i: Because you will find here that sometimes the doctors and nurses would rather than be sympathetic towards you will say ‘well I told you not to bloody well do that thing before’. I’ve seen it in the hospital, accidents come in and here’s the nurse screaming at the poor guy suffering, you know that sort of attitude, rather than be sympathetic and be pleasant. For example, if I am at the doctor and the doctor turn around and said ‘I bloody well told you not to eat that sort of stuff, I’ve bloody well told you before’. That’s enough – here you are suffering, you face the doctors or the nurses screaming at you, whereas the overseas doctors seem to understand how to handle the situation.

Evelyn: OK, do you think because of that some people might avoid seeking hospital care?
Ta’i: Exactly. Some of them don’t want to go and stay in the hospital.
Evelyn: Because they will get told off?
Ta’i: Yes, because of that sort of attitude.

The experiences between participants and doctors also led to a degree of opposition from three participants. Solomon and Tu resisted and challenged the advice they had been given. Ignoring medical advice became a strategy of coping with the reality of having to independently manage their health condition amidst many obstacles.

Solomon: I’m going to die you know (from diabetes)... I’m kind of one of the silly boys that say I would rather die happy.
Tu: I will fight this (diabetes and renal failure) myself. At least I’ve reached to my 50s.

This opposition to medical advice combined with levels of denial about the seriousness of their diabetes led to great risks being taken to challenge their own physical responses to the disease. Unfortunately for Tu (see Case study 4) these risks, combined with the severity of his diabetes led to renal failure and a reliance upon peritoneal dialysis.

Tu: I refused to take my injections and my tablets... I've got my injection... for my energy cells in my body. I do not have enough red blood cells in my body. I need to inject myself three times a week with that otherwise... from here to there (signalling the length of a small room) I'd be out of air. I'll be puffing and sweating and that's what I use. I thought I'd bring it in (to the interview) and of course, this is only for decoration. I never use it... I never use it. Only when I feel so tired then I use it just to check my blood and then inject myself.

John (see Case study 1) also challenged medical advice shortly after being diagnosed with diabetes. John understood that missing his medications for up to several months at a time because he “couldn’t be bothered” and “being stubborn” led to the early onset of his renal failure. Even after renal failure, the participant tells three stories about taking risks with his physical body. In the first story John relays the turn of events that caused him to get a peritoneal related infection whilst back in Rarotonga on holiday. The second story highlights his desire to control his body and to test its limitations after receiving treatment for renal failure. John’s comment regarding setting up his own dialysis inside the clinic setting illustrates his need to retain some autonomy over his body.

John: You don’t want to go through that, it (kidney infection) was really bad, like someone operating on you, you know without you know, anaesthetic and all this you know, really painful. And of course I was supposed to dialyse in an enclosed area but I was doing it outside on our veranda you know. Not really taking um, um, you know it was funny, I was dialysing one day and was outside on our veranda and the dog sitting beside me. (laughs). That didn’t help, yeah. Because I was told to dialyse in an enclosed area but I was dialysing while having something to eat with my dog. Even I used to dialyse at home, do my own dialysis. And um, I got to one stage and I think I was playing with my own life. I wanted to find out how long I was going to survive without dialysing. So I tried, I was supposed to dialyse three times a week. So I cut it down to two. And I cut it down to one week. And then I didn’t even dialyse and that’s when I started to feel ooo you know, I was starting to really get sick. And um, I ended up in the hospital.
Evelyn: Why do you think you did that?
John: Ooo, just a dare I suppose. A lot of, I heard people were saying you can only survive two or three days without dialysing. Ok, I’ll give it a go (laughs). Most stupid thing I ever have done (laughing). So yeah I did survive the whole week. I think I went up to eight days without dialysing. But, that was dangerous.
Evelyn: What did they say in the hospital?
John: I got a good growling from the doctor. And they took my machine away from me and they said no, you are going to the hospital to dialyse now. So that’s why I am back in the hospital, but no, I am glad. But I still do all my own set-up, I do all my own needles and all that. But um, I am glad that I am back at the hospital.

John’s risk taking was also described in a different setting:

John: It’s funny, I dared myself to eat those fish (laughs). Me and my mate, parrot fish and all that we got on the reef. Because of fish poisoning you, know there is fish everywhere they don’t go on the reef anymore, so we caught a couple of parrot fish. Took it back, cooked it, looked at it and said what do you think? Ah, let’s eat it. We ate it and then we waited an hour. Few hours, nothing happened. There you go mate, there you go. And the funny thing, a few days after that we caught a small koma (reef fish). We caught it and fried it. Eat it. After a couple of hours, just the tiny fish, we got hit by it. Some only two days we were vomiting and all this scratching and itching and all this. But after that it was gone. There’s a lot of people that got hit by it bad. By the fish poisoning... I know one family that the dog died and I think the husband died too.

The participant accounts which have featured in this section speak to the barriers of seeking health services based upon perceptions of individual health and relationships with medical systems and in particular, doctors, and high risk taking behaviour. Overall, the patterns of delayed diagnosis due to denial and avoiding a degree of shame is exacerbating the threat of diabetes and associated health conditions such as renal failure. Furthermore, the reluctance that some participants had towards treatment is another obstacle to minimising the health effects of diabetes and possibly reactivation of latent TB. The pattern of the Cook Islands participants delays in seeking health services and diagnosis is consistent with the issue raised by Tukuitonga and Finau (1997) about Pacific people presenting later than the general population of New Zealand and having more complicated issues. In Auckland, a study by Lawrence (2007) revealed that reactivated TB among refugees was because of the culmination of ‘multiple layers of disadvantage’. I argue that the reluctance of treatment for TB and the maintenance of diabetes poses a real threat to this syndemic in
the future. The risks of delayed diagnosis when seen to also interact with multiple layers of
disadvantage will magnify increased associated health conditions, increased risk of diabetes
trigging latent TB into TBD (Restrepo et al. 2006) and more complex paths to diagnosis and
treatment of TB and/or diabetes in Cook Islanders.

Cook Islanders’ experiences of health services post diagnosis

As with most diseases and health conditions once a Cook Islander has been diagnosed with
TB and/or diabetes it changes their body, their emotions and personal relationships and
affects their lives in distinctly new ways. Two participants living with diabetes in Rarotonga
felt the health system’s ability to provide support for those living with diabetes was lacking.
The emphasis, they believed, rested too strongly with prevention, while those living with
both the physical and emotional manifestations of this disease felt they had no “place” in
the health system.

Tupou: Well we actually tried to form a society which is still on-
going, a diabetic society here, and I am one of the founding
members, but it’s a dead sort of thing because the presidency is
really not active so the society has really been dead for the last five
years or so since it was formed.
Evelyn: What was its purpose when it was being formed?
Tupou: It was to encourage diabetics to get together and talk about
this and Karen (Cook Islands Ministry of Health Nutritionist) was one
of the main instigators of the whole thing but as I say when they
were shifted around I think she wasn’t able to contribute (financially)
but that was the idea, to get the diabetics together.
Evelyn: And did it provide support do you think when it was
running, was it a good thing?
Tupou: Well it only ran for a couple of months I think... as I say, if
there was a clinic, if the society has actually come to this and you
could go to the clinic, you could go there and get the information
and a proper, I think a proper person, a proper doctor who knows
about diabetes who is not involved in any other things and sit down
and talk to us people because sometimes the doctors are multiple,
there’s nobody really, I mean they are trained in that, there’s not
enough, like previously an older doctor who was diabetic but you
would go there every day and he would repeat himself and then
you didn’t want to listen to him. He would pass on all the
information to you – this is what I do, I wake up at six o’clock in the
morning – that’s not really what you wanted to listen to. And a lot of
the awareness programmes, like I say it’s in the media, not many
people listen to the radio, not many people read the papers, that’s
why I say you need a clinic where we could go there and actually
listen to each other and sort out our problems with our diabetes and how we are managing it – I think in that way you would get the message across to each other.

Evelyn: Do you think that ‘outsiders’ (people not from the Cook Islands) are in a position to do that?

Tupou: Yes, sometimes it’s better because we will listen. If it’s our own people they say “what do you know about diabetes?” You know, that sort of reaction. Or “who cares what you say”. We tend to listen to other people more. I don’t know what it is, maybe because of the closer relationship here, they say “oh go away, we don’t want you”.

Interestingly, Tupou repeats the need for a ‘proper’ person three times. In the same conversation, Tupou talks about the different perceptions local people have of ‘outsiders’ or foreign doctors. They are perceived as being more knowledgeable, professional and efficient. Previously, the notion of doctors in the Cook Islands being “Big” people of higher status was highlighted. Because of the relative distance between their patients and the community compared to local doctors, foreign doctors are perceived to be of an even high status but also more confidential. Interestingly, although also perceived as “Big People”, the Rarotongan participants in this study preferred and trusted treatment from foreign doctors. It could also be the case that a ‘proper’ person refers to a preference to doctors instead of local nurses.

Another participant also expressed her interest in establishing a TB committee. For her, this committee would allow people who cared for a person with TB or those who have had TB to come together and share experiences. For Cook Islanders, there is a desire to mobilise, educate and support people with experiences of disease through the formation of committees. For these participants, being heard and having a place within the health system is a priority. In order to work towards minimising the isolation that Cook Islanders with diabetes experiences, collective responses to changing food and exercise behaviours would be beneficial both in the Cook Islands and in New Zealand.

In Auckland, two participants had new positive housing arrangements emerge out of being diagnosed with TB. Both these households had been ‘off the radar’ in terms of the unsuitable housing that had been supplied for them by Housing New Zealand. With the

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29 In the Cook Islands, foreign doctors are not necessarily from New Zealand. During the time of field research there were doctors from Myanmar, Russia, Italy and Tonga.
advocacy of Public Health Nurses, Anabelle’s flat was re-carpeted and fitted with a ramp and disabled shower and another family was found a four bedroom house of their own for their 8 person family. Before the children were diagnosed with TB they had been living in a two bedroom flat with another family. As well as overcrowded houses among some of the participants in New Zealand, there was a degree of inadequate housing across the transnational social field. The observations of inadequate housing included reliance upon cyclone shelters or tents in Aitutaki and leaking houses in times of high rain fall in Rarotonga. As Kearns et al. state:

In the absence of adequate and affordable housing, health is endangered; there is no security from physical adversity or human abuse; and everyday life processes such as education, socialization and interaction are jeopardized (1991, p.369).

For Tu in Porirua\textsuperscript{30} undergoing dialysis treatment at home meant he was able to receive a heat pump for his house. This heat pump was placed in the lounge where he sleeps while he dialyses overnight. This conversation raised another issue for this participant, his inability to pay for the cost of using the heat pump while on his benefit. Housing issues are not confined to physical space, but also being able to afford utilities. In the background of many interviews was the relationship between adequate housing and health.

Evelyn: The heat pump is affordable to run, or?
Tu: Well, August this year was very, very cold for us, the average temperature was about seven and our power bill was $480. I needed to keep warm, I've got oil heaters in the room for the kids. We all ended up bringing all the mattresses down inside there (points to lounge) 'cause that's where the heat pump is.
Evelyn: That's a lot of money isn't it?
Tu: That's a lot of money especially when you are not working. 'Cause all I get is the invalid benefit and our rent is $231 and that comes out of my invalid benefit so by the time my other deduction is taken out I am left with $24 a week. So my wife pays for our power bill and our food and my son is working and my daughter is also working to help out.

During this interview with Tu, like many others, accommodation issues were raised in relation to health. For Tu, this includes both the suitability of the physical space, but also being able to heat the house in the winter. A heat pump was provided to help reduce these costs, however, in doing so, heaters in the four bedrooms were no longer used and

\textsuperscript{30} Case study 1
the whole family was sleeping in one room of the house. At the time of the interview, this would have meant between five to six adults sleeping in one room each night. When asked about money to afford heating, Tu was able to describe his financial limitations as well as how his family contributes to the overall economic strategies of the household. This short piece illustrates the need for research between health and housing to take wide approaches which include factors of affordability and household economic strategies in the face of financial constraints.

For Sam31, seeing the same General Practitioner (GP) in Auckland three times resulted in misdiagnosis. Sam was very ill for three months with flu-like symptoms, fluid on the lung and dramatic weight loss. His local GP prescribed him antibiotics and told him to rest at each consultation. Eventually his girlfriend Mele took him to Auckland Hospital, where he was once again misdiagnosed for three weeks with pneumonia. Eventually it was discovered that he had TB.

Evelyn: Do you remember what the GP said?
Sam: Oh yeah, I forgot about that, the GP just said that there is nothing wrong with you, just take these pills and you will be alright. See this is the fluid in my lung and what he thought was that if the pills get in there that they will take all that fluid away. But all the pills were doing was just hitting that wall, it wasn’t really doing anything. Evelyn: So even when you went back again?
Sam: He just kept giving me the same pills as last time.
Evelyn: Which GP was that?
Sam: Glen Innes.
Mele: (name)Health Care. But I wasn’t actually with him for those days. He kept going and coming back with the same results. So I was like, I’m going to take you to the hospital. Because he’d never been to the hospital before he didn’t know it was free so he was kind of scared. Oh, I’ll take you. I’ve been to the hospital heaps of times.
Sam: Yeah that was my first time.
Evelyn: You didn’t think it was free?
Sam: I just didn’t know anything, ’cause that was my first time ever been in the hospital.
Evelyn: Really? Even to visit someone?
Sam: Nah, maybe, I don’t know.

31 Pseudonym
The reason behind this participant’s misdiagnosis is uncertain. It highlights that even in areas of Auckland\textsuperscript{32} where TB is more prevalent than other suburbs; GPs are not always thinking about the possible threat of TB disease. Sam’s inability to recall any knowledge of how the New Zealand hospital system operates even in the throes of being so ill demonstrates that basic information about health care has not reached some people in New Zealand.

For the participants on dialysis treatment, their conditions mean that they regularly rely on the availability of treatment and associated materials, equipment and expertise. This high use dependency on the health system in New Zealand has changed their ordinary experiences of travelling back to the Cook Islands. The Cook Islands does not have the facilities for dialysis. Poor water quality, lack of equipment and technical and medical expertise mean that it is more feasible for these patients to remain in New Zealand. However, two participants have responded to this by finding flexible strategies within the health system. Tu decided to have a peritoneal fitted so that he could, when financially possible, arrange for all his equipment and fluid to be transported to Rarotonga.\textsuperscript{33} The peritoneal fitting allows Tu to administer his own dialysis treatment at home and to take his equipment and fluid with him if he decides to travel away from home. Similarly, John goes to Rarotonga for three days at a time between treatments and is also working on a fundraising initiative to help raise awareness about renal failure and a future solution for a dialysis treatment facility located in Rarotonga. For both John and Tu, the ideal they are working towards is to live in Rarotonga permanently. At this stage, the only solution for this is a kidney transplant.

John: Not long ago because I was talking about my idea of fundraising to get some machines. And um, he (friend who is involved in government in the Cook Islands) said, the government had been researching that too, and it is very expensive for home. And not only that, but because at home we have problems with our water. Because the machine uses a lot of water and because back home we always have problems with our water tank and all that. And not only that, but getting people to go over and train there’s a lot of cost and money involved in it. But anyways I had a chat with a

\textsuperscript{32} This participant used local health services in Glen Innes.
\textsuperscript{33} Dialysis fluid is introduced via a permanent tube in the abdomen and flushed out either over night while the person sleeps or regularly through the day.
lot of my friends in entertainment and all that and they are willing to help. But at the moment, things are on hold. Because of that problem that we have (with water sanitation). I had a chat with one of the nurses over here because I was asking about Samoa’s one and she said that the Samoan units were sponsored by China or someone there. And because they have the money to do all this and besides in Samoa they do not have problems with water. But back in the islands we do have that. So everything at the moment, it is on hold.

The issue of dialysis treatment for diabetes patients raises questions about nation centred responses to health services. It also spurs on reinvestigation of the roles and responsibilities of national and international health organisations and how they can facilitate primary, secondary and tertiary health services for mobile populations. The narratives above highlight that access to dialysis treatment in the Cook Islands is high on personal agendas, and it was also covered extensively by participants representing the International Development Group of the Ministry of Foreign Affairs and Trade in New Zealand and the Counties Manukau District Health Board (see chapter eight).

Overall, a common theme was that for people with TB and/or diabetes their experiences with their bodies became politicised in new ways. Navigating both health services and general society is different for people living with, or having had experiences of diseases. On a small island, the size of the medical system can potentially work favourably for people with TB and/or diabetes. Primary health in these places takes advantage of being able to access medical and family history easily with such a small population. The links between peoples’ personal issues of housing and health are also more visible when PHN work within peoples’ homes. However, the scale of the place may also increase the possible stigma experienced, testing and treatment may have to occur away from home, or in the case of those receiving dialysis treatment, some people may never be able to live on a small island again.

In a metropolitan city, the complex and often disparate sections of health services are perceived as daunting for many Cook Islanders. Despite this, Cook Islanders attribute the New Zealand medical system with a level of expertise not able to be accessed in the Cook Islands. The connections between the two health systems and the movement of Cook Islanders have altered people’s expectations of health services, and movement between the
two countries for medical services is now a common practice for Cook Islanders with a referral or private financial resources. The mobility of foreign doctors to Rarotonga and the outer islands provides Cook Islanders resident in the Cook Islands with a standard of care that they have come to expect. For those with the available means, travelling to New Zealand for health services is often a logical decision to make.

Biological, cultural and political relationships with food

The case studies in the previous chapter extend the understanding of lives of people with either or both TB and diabetes. The issues of barriers to employment, inadequate housing and the cost of heating in New Zealand intensified family illness. In addition, social isolation and corresponding low self-esteem also appears to play a role in this syndemic. Gonzalez-Guarda, Florom-Smith and Thomas, believes “it is possible that higher socio-economic status and one’s standing in society influence ones’ own sense of self and control over one’s life which in turn leads to health promotion or risky behaviours” (2011, p.371).

The syndemic framework brings to the surface the chain-like links of interaction between disease and living conditions and the different manifestations of poverty found to worsen the experiences of disease for Cook Islanders. The corresponding benefit of conceptualising poverty’s role within a syndemics approach lies in the prioritisation of the different culturally specific conditions of poverty.

One of the most repeated patterns within the TB, diabetes, transnationalism, food and poverty interaction were narratives about an inability to provide nutritious food for themselves and their families. Keeping in mind Restrepo et al.’s (2006) assertion that TB and diabetes both preferentially affect the lowest socio economic strata, the lack of affordability of nutritious food can be seen to exacerbate this syndemic. Pollock, when writing about contemporary changes in diet throughout the Pacific states that “Western gastronomic influences introduced a drastically new set of ideas and practices that became major commercial intrusions (2008, p.110)”. During my research it was common to see bulk food purchases in the kitchens of participants, and large quantities of fried food providing an early dinner for children arriving home after school both in the Cook Islands and in New Zealand. The underlying commonality is that this type of food is cheap, and when multiple members of the family are working, it also provides a convenient option for families. Healthy eating on limited resources requires a large amount of organisation, and when
numbers in the houses where relatives come to eat, stay or live fluctuate frequently; a flexible alternative needs to be at hand. In the case of diabetes care, Marjerrison et al. argue that:

Diabetes care is demanding for any family, and is particularly challenging for families with limited financial resources who struggle to maintain access to adequate amounts of safe and nutritious food (2011, p.607).

The main co-conspirator of obesity is diabetes (Candbid 2007), which, when combined with poverty can amplify more serious health conditions. While most of the experiences of diabetes are situated within the person afflicted, changing the food behaviours for Cook Islanders needs to be situated in a communal context. In the homes of the participants I was able to observe the relationship between participants and food in a home setting. For example, upon visiting Solomon in his home in Porirua, for the first time I noted:

_Research diary entry 9 December 2011_

He drank his tea out of an old beer pub jug with the tea bags (3) left in. There were five loaves of bread on the table and one donut. In the kitchen I noticed two deep fryers on a bench in a prime position for frequent use.

Within this study food behaviours featured strongly in relation to health, culture and ceremonial ways of life. At the core of the discussion regarding experiences of disease and food was the issue of affordability and time constraints. Participants tied together ideas of lack of money, their relationship with food and the interaction between nutrition and their bodies.

Kiri: And that’s where, because that’s the challenge for health promotion, eh? And the dieticians as well, because of the cost and you know the value in the fruits and veggies but then the reality that has been presented to our people, where she says shop and create recipes with the fruits and veggies of the season. So if it is a season for this particular group, for pumpkins, then have food and meals around fruits and vegetables of the season. So it’s going to be a change of style, a change of thinking for our people. That’s the drive but you could still have your favourites. You got your favourites and to save as well. Definitely going to the market but as for people like myself, you know this is the only day that you can get to sleep in, my Saturday that I can sleep in. So some day is fine but my Saturday is my sleep in. So for the people like ourselves who don’t go to the market, but here’s this education here. And I wonder how much of that education has been given to our people
in the Cook Islands. Because it’s shocking every time we go back home when we do go home to see our people, oooh, they are just growing. The children are growing. And they are becoming like NZ life now, you see them going to the fast food. (Yes, yes from others). Takeaways. Going to get their meals from the Punanga market. And back in my days and that was just a couple of years ago, many moons ago for my parents around the table here, we were planting. We were planting our veggies. And during my dad’s time twenty years ago, I was still planting. But to see my generation and the younger generation, fast food! And they are growing in size. Makes me wonder, how active really is the health (system) back home. You know in the education talk with those selling these foods, because it’s heaps. You can get a big meal for just $5.00 or $7.00 back home. Yummy for them and for me, I was eating it there because I know I won’t be eating it here in NZ. I was on holiday; it’s a time for a treat. But then you have the locals saying every week. Now they got their everyday provision. They are not even cooking their taros from home. Just buy it from the deli or the supermarket, you don’t even need to go to the market. It is just in the shops. Whoa! The green bananas even, green bananas, they can buy. I said, “what is becoming of our people back home?”

The above account contains economic and cultural descriptions of the challenges Cook Islanders face both in New Zealand and the Cook Islands in search of affordable and healthy food. From Kiri’s position, acquiring fruit and vegetables requires both financial and time strategies combined with adequate health education which she believes may not be filtering through to families. Whilst back in the Cook Islands, Kiri offers her own interpretation of why Cook Islanders are growing in size. “They are becoming like New Zealand now” refers to their physical size and the type of lifestyle they are living where subsistence agriculture and a slower pace of life is no longer readily accessible (due to both change in life style and local economies altered through international trade agreements). It may also imply that desires for food that are accessible in New Zealand such as takeaways are now more normalised. Even in Aitutaki where you would expect high levels of subsistence agriculture, takeaway establishments can provide convenient options for lunches and dinners. Implicitly the account also signals a change in lifestyle and daily food habits. Kiri mentioned that she does not attend the markets in the weekends because Saturday is her rest day in between full time employment Monday to Friday and church duties on Sunday. It appears it was less obvious to her during her recent visit to Rarotonga, that the increase in purchasing prepared meals in Rarotonga is often a result of similar time
constraints. It is not uncommon for mothers and fathers to both work multiple jobs, giving them less time for both food preparation and gardening. Her interpretation may appear judgemental, however, her final question regarding ‘our people’ connects herself and her family with her kin ‘back home’. These sentiments that demonstrate an awareness of the fluidity of people and practices of Cook Islanders between the two countries has played a role in the lifestyles and health issues of Cook Islanders.

The literature confirms Kiri’s observation that poverty, urbanisation, migration and increase in weight are possible interdependencies (Candib 2007). The urban environment in New Zealand and the increasingly urbanised behaviours being adopted by Cook Islanders in the islands (motor scooters, western food) have had an impact on the weight of Cook Islanders and the health conditions associated with obesity. Globally, diabetes and obesity can be used as a marker of the health inequality dominating low income, immigrant communities of colour (Candib 2007, p.547). Contemporary approaches to public health individualise the health issues of obesity and corresponding diabetes. This has obscured the interaction of other influential elements such as the realities of living in a transnational space, being poor and having food behaviours heavily influenced by cultural norms and family practices. The interaction of these dynamic mechanisms needs to be considered synergistically to appropriately design interventions to diabetes and TB, given that adequate nutrition is a solid foundation to a healthy life. Food security and providing adequate nutrition in an environment where all these pressures exist is often outside of people’s control. Entering the homes of people for this study illuminated the constraints Cook Islanders frequently face when providing nutrition to themselves and their families. The constraints included visible displays of poverty and the resulting lack of financial resources, interacting with limited access to health services, mobility, urbanisation and weight gain, constrained healthy choices, inadequate housing and an increase in associated health conditions. As Capstick asserts, “one pertinent illustration of biomedical tenets coming into conflict with cultural norms in the Pacific is in the case of food and eating” (2009, p.1342). In the next section, it becomes clear that the relationship between food and health is more than nutritional. As Pollock states, for Pacific peoples:
Food reinforces ties between Pacific peoples and their island homes, while linking them to a wider world. It links families through exchanges and shared ideologies and diversifies over time and space. Increased options of foods from the land or from the supermarket are part of that diversity... Food is an identity marker that both links families overseas to their island home and distinguishes the two communities (2008, p.103).

Food and nutrition

Poor nutrition has serious consequences for health, and nutrition is clearly a factor which needs to be included as a potentially harmful mechanism within this syndemic. Poor nutrition, a result of many interdependent factors, interacts explicitly with both TB and diabetes (Hu 2011; Rock 2003; van Lettow et al. 2003). The strong link between nutrition and immune system function positions nutrition as a key mechanism towards a healthy population. With TBD, appetite is lost and nutrition compromised; with GDM and diabetes, lack of control over glucose levels can lead people towards unhealthy food choices. The transnational behaviours of Cook Islanders and the increased access to calorie dense processed food has also altered the nutrition behaviours of this population (Hu 2011). This is strongly recognised by health promotional activities relating to nutrition in both countries, where traditionally grown or healthier options are promoted. However, there still appears to be disconnections between possessing this knowledge and behavioural change.

In this study the term nutrition refers to the role nutrition plays in producing or exacerbating diseases. The role of nutrition in the diabetes and TB syndemic depends upon which disease(s) are present. This signals the need to unpack the biologically and socially constructed ideas of the role of food in health. In the case of diabetes, nutrition most likely concerns the over consumption of calorie dense food over a length of time. For people with latent TB and TBD, a balanced healthy diet is necessary for both the prevention and treatment of TBD (van Lettow et al. 2003). Thus, inadequate nutrition can lead to both TBD and diabetes (Cundy 2008; Hu 2011). One of the most serious observations in this study was the relationship between inadequate housing and nutrition. In situations of overcrowded living conditions, participants found it difficult to provide their family and extended families with a balanced diet. In New Zealand affordable housing is one pathway to limited resources for nutritious food and an example of the “endangered”
(Kearns et al. 1991) relationship between health and housing. It can also be argued that the quality of food (Hu 2011) purchased by participants in these situations was part of wider discounted (Cheer et al. 2002) living conditions.

As outlined above, nutrition not only interacts with the biological body, it is also influenced by wider socio-economic factors. For this reason, this chapter suggests a reconceptualisation of the role food, eating and diet plays within this study. The particular daily demands of the participants with either/both TB and diabetes indicated that socio-economic vulnerability heavily influenced decisions and behaviours about food and diet. In this way, affordability of nutritious food across the transnational social field needs to feature more prominently in health related policies in both countries. Marjerrison et al also argues that diabetes care is demanding and, if present in a family which has difficulty accessing safe and nutritious food, it can present a real challenge (2011, p.607). This is a type of food insecurity, which according to The United Nations (1998) is defined as the lack of physical and economic access to sufficient, safe and nutritious food preferences for an active healthy life. In the context of this syndemic, food insecurity may manifest as a result of population mobility, household overcrowing, unemployment due to illness, associated high costs of travelling to doctors and hospitals, medication expenses and financial constraints. As such, the syndemic framework reveals that real barriers exist to food security for Cook Islanders.

**Food and Cook Islands culture**

The fear of how others will treat you, particularly at social gatherings where food is involved was pervasive for participants with diabetes. In a culture where food is central to family and social life, participants found themselves having to redesign their relationship with not only food, but also their social world upon finding out they had diabetes. In the social world, the responsibility to independently manage one’s diabetes is still strongly asserted by both the medical system and wider society. As diabetes reaches epidemic levels in some developing countries, strategies to encourage the collective responsibility of these populations struggling with this health condition will need to be designed. Anecdotally, one participant (Solomon) knew of other family members with diabetes, but not the diabetes history of his father. Solomon did not discover this until he found his diabetes medication whilst clearing out his house. It was recognisable to this participant because it
was the same medication he was prescribed. Solomon believed that his father’s desire to conceal his diabetes was because of fear of judgment. This raises the question of why Cook Islanders are judgemental of people with diabetes. Within the narratives, the source of this judgement was both written and practiced promotional material, which positions diabetes as a condition of ‘individuals’ who have made bad ‘lifestyle’ choices.

In the narrative below, it is clear that food was so central to Solomon’s life that changing his relationship to food has been more difficult than both an alcohol and tobacco addiction. Without the freedom to eat the portions and types of food that Solomon enjoys, this participant felt that his life was over. The respite Solomon would experience from his diabetes would occur after he died:

Solomon: I said [to the dietician], “God, you told me to lose my drinking, I lost my drinking, you told me to lose my smoking, I lost my smoking. And now you tell me to have only one piece of chop, God, I might as well go and die.” I said that to the doctor, I might as well go and die. God, gees, I don’t know whether you are trying to help or trying to kill me. I mean that’s what I thought. ... Gee, I’ve got rid of my drinking, I’ve got rid of my smoking, but the eating part. That is always the part that I always say to my dietician, “Yeah, it wasn’t hard for me after a while of giving up drinking and smoking, but the eating, God! I don’t know why?” Yeah, that was the hardest part... I know one thing, there’s no diabetics up there [pointing skywards towards heaven].

Food and eating at cultural events hold a prominent position in Cook Islands culture. Therefore, being diagnosed with diabetes disrupts a person’s normal engagement with their social worlds. Solomon’s father concealed his affliction in an attempt to avoid discrimination or judgment. The stigma experienced by participants included internalised feelings of shame and worthlessness and feeling rejected or embarrassed in relation to other people’s perceptions of them. Examples of feeling isolated and overwhelmed were told by the participants through stories of attending cultural events as a diabetic. In the narrative below, Solomon’s wife describes her contributing role to some of Solomon’s feelings:

Evelyn: And do you [Solomon] still enjoy going to birthday parties and things?
Solomon’s wife interrupts: Oh, he doesn’t want to sit beside me [at feasts] because I always tell him off, especially for touching the pork. If I called out for him to come and sit beside me he ignores me [much laughter] and goes and sits somewhere [else]. But to be
honest sometimes if I see him touching the pork I go straight up to him and tell him off. I don't care if people watch me. I said, “Don’t touch that.” I mean, you don’t want to lose your partner, to be honest, that’s the main reason why I’m trying my best to encourage him to listen to me.

The stigma and fear of judgment is so powerful for some of the participants that it reduced different forms of activity and compounded social isolation. Being active was reiterated in health promotional manner as a key strategy for managing diabetes by three participants; however, “active” for Cook Islanders means not just physical exercise but also being active in community and church events and as a result of their diabetes, participants would often refuse invitations to social gatherings. Another strategy employed was to eat before going because they don’t want to be judged for what food they decide to eat when they attend.

Tupou: Well, that’s another issue because, the missus knows about it too, she’s aware of diabetes and what to, and what not to do, but she’s coming on “stop it, don’t eat this”. I say eh, none of this none of this. I said it’s not going to be a big change in my lifestyle, it’s like going to be taking little bits [changing habits slowly].

Solomon: Well you know, it’s been a problem, I still have a problem with my eating. That’s been the greatest problem in my diabetic life. But I suppose, all my life really. I love eating… Before I was really active, going out and into sports and everything. Now I just don’t go out to birthdays and weddings, I just don’t feel like going out. I just stay home, I send my kids.

Tu: Yeah, I mean, to me I actually control what I eat and one of the best ways that I found is avoid any invitations. That’s why you guys don’t see me at a lot of Cook Islands’ kai kai [feast]. I don’t wanna be there. If I do come there, I’ll end up eating pork. I stay away. I stay home. I send my daughter. Even when I came to a wedding, one of my nephews, I just stood there and watched everybody getting their plateful and they couldn’t understand what the hell I was doing. And then one of my nieces said, “Uncle, are you going up?”, and I said, “Yeah, I’ll go”. I wait until everyone had finished, I was hoping by the time I got to the table, nothing was left.

Community and cultural events are important elements of local and transnational life for Cook Islanders. The isolation that people with diabetes experienced signals that participants felt differently towards these events post diagnosis. Instead of excitement, the participants felt dread and if they did attend, they worried about being judged. It is a difficult situation, because if they refuse kai kai (feast), it may offend others, whilst if they do
eat, they risk judgment or reprisal. Community and cultural events are recognised for their ability to raise the profile on health and social issues, therefore it is worrying that a section of the community may not feel at home and may indeed retreat from these events.

The complex nature of diabetes as a disease combined with the necessary lifestyle changes causes confusion. While medication can help manage this condition, the reality of the changing relationship with their own bodies and their social world was a new experience for all of them. Previously, the issues participants had with their physical bodies were short-lived and with the help of medical intervention “cured” or “fixed”. In the case of living with diabetes, very few were able to manage this solely through diet, and the majority were experiencing worsening associated health conditions.

For the participants with diabetes, the future was uncertain. Diagnosis recalibrated their relationship with their own body, their relationships with their family, social world and, overwhelmingly for my participants, food. Keeping in mind the importance of food in Cook Islands culture, this reorganisation of their lives is extremely difficult. What makes this experience all the more difficult is receiving inconsistent and often conflicting advice from clinicians, family members and the wider community.

The relationship between food, Cook Islands culture and experiences of diabetes highlights how difficult it is for the participants to balance their relationship with their biology, food, cultural events and self-esteem. The exhausting task of independently balancing these dimensions (or weighing up the risks) several times a day independently without group or family support played on the mind of many of the participants. I believe that this causes further isolation and lowered self-esteem for Cook Islanders.

Food, fear and stigma

TB and diabetes change not only participant bodies, but also their social realities. Stigma is a powerful force in both small and large communities where denial and the stigma of TB can be implicated in the increased transmission of TB (Hill and Calder 2000). Stigma is a pervasive force upon those with diabetes and/or TB and the participants in this study were very upfront about the ‘shame’ they had experienced with health services, at community events and in the home. Many felt they were never far from the judging eye of someone
monitoring their behaviours. The level of surveillance expressed by participants with regards to their food behaviours meant that several of my participants had retreated from both health services aimed to assist the management of their diabetes and community events. Goffman argues that the different types\textsuperscript{34} of stigma share the same sociological features:

\begin{quote}
... an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated. (1970, p.5)
\end{quote}

According to Camp et al. “Goffman stressed that stigma should be understood in terms of relationships, since it refers to a process of social rejection, devaluation or discrimination” (2003, p.823). During this study, Cook Islanders living with diabetes described many scenarios where they had experienced stigma and corresponding emotions. The participants’ emotional responses to this stigma included shock, fear, worry, hardship, confusion, hopelessness and victimisation. Much of the worry, fear and hopelessness arose from what Camp et al. refers to as “the relation between stigma and the self” (2002, p.823). In particular, many of the participants had been affected by self-stigmatisation and as a result had very low levels of self-esteem. They were aware of the common ideas associated with diabetes in the Cook Islands communities and anticipated people to perceive them as “fat”, “lazy” and solely responsible for their health condition. In combination with this awareness of the negative impression others have of them (Camp et al. 2002) some participants also expressed being subjected to what Nichter describes:

\begin{quote}
... a process of blaming and “othering” that stigmatises groups and reinforces preexisting prejudices and group animosities (2008,p.45).
\end{quote}

The fact that stigma in relation to diabetes arises from both self-identification and prejudice is worrying, particularly if this translates to a personal barrier of seeking health services and retreating from social life (Lawrence 2007; Wanyeki et al. 2006). It is important to mention that emotive stories were more frequent with those with diabetes than those with TB. For participants with both, the emotional experiences of living with diabetes often surpassed the experiences of living with TB. Repeatedly, those living with TB found reassurance in the

\textsuperscript{34} Summarised as stigma relating to the body, character or behaviour and race (see Goffman 1970).
concept of “being cured”, although the complex and dynamic nature of the TB bacteria did cause some of my participants “worry” about the uncertainty of future infections. Because the timing of my interviews was either after or towards the end of their TB treatment, all participants were experiencing some sense of relief from the disease and treatment. If I had spoken to the participants at the time of diagnosis I would expect to have uncovered a range of different emotional responses.

Nevertheless, examples and experiences of stigma were highlighted through interviews with participants with TB. My research diary entry below deals specifically with TB and highlights the relationship between fear, stigma and not understanding their medical condition. Although this entry pertains to TB, similar explanations were provided by those with diabetes. It relates to Rangi and his family’s enduring experiences of the TB and diabetes syndemic which featured in Case study 5. The similarities of stigma between the diseases relates strongly to the participants fear of judgement from their community.

**Research diary entry 11 August 2011**

Rangi told me the story of how he was too “shy” to tell anyone at his work in the Ports of Auckland that he was being treated for TB. In a very confused way he told me that because his TB was “not bad”, the nurse said it was OK and that he was not a risk to anyone. I asked why he felt shy about it. He said that because he didn’t really “know” TB. He didn’t understand the disease and so he knew that other people didn’t as well. He feared that people would think it was more serious than it was. He went on to talk about how when you have the “flu” you know what to do, but with TB, no one knows, you can’t tell you have it so you don’t know what to tell the doctor. I questioned on this line some more and what surfaced was that Rangi didn’t have any previous experience of the disease, no background knowledge to reference when the family got the disease. This made him frightened because “I knew the word TB, I knew it was bad, but I didn’t know about it”. This highlights the pervasive strength of stigma. Rangi’s knowledge of TB was one of fear. Even now, after having TB, Rangi still admits that he doesn’t understand what happened with the family. I told Rangi, that TB is a very complicated disease to understand and that many people did not understand their condition. He seemed relieved about this.

In the Cook Islands and among Cook Islanders in New Zealand feeling ‘shy’ arises from either being embarrassed, afraid of judgment, or in many cases a combination of these. After a discussion with Rangi I was able to uncover the many interrelated reasons as to why
Rangi was ‘shy’ about TB. He was in the unfortunate situation where many compounding factors had led to both TB and latent TB affecting himself and his young children (see Case study 5). His reluctance to tell people at his work arose from three different positions. First, he could not accurately explain his TB status because of his limited understanding which in turn meant that he could not fully explain that he was not contagious (because he had latent TB or “not bad TB”). This led me to believe that the diagnosis of latent TB did not fulfil the function of giving Rangi some certainty about his inability to actively transmit TB. Second, he was fearful that he would lose his job. The third reason related to the judgment he expected he would endure because he felt he had failed to protect his children from this disease. Rangi expressed this as an inadequacy and embarrassment at not understanding why his family had “got TB”. The pressure that Rangi experienced as part of dealing with TB was influenced by his own internalised feelings about the disease, confusion and historical understanding of TB being "bad".

Fear was also very present for Anabelle, who had lived her entire life in Mauke until she was aged 60.

Anabelle: I was frightened you know and I was surprised too. I never expect that I got TB because I'm old. And I said, "how come this sickness come on the old people?"

Her later life migration to New Zealand explains some of her uncertainty around TB and her historical reactivation of latent TB and also explains her fear, given that in her lifetime, TB was more common during her childhood but not something that would have been common more recently. The history of Anabelle reminds us that people’s emotional responses to disease need to be contextualised. Anabelle, had more than likely heard stories relating to lonely experiences of TB treatment. Park and Littleton heard one such account during field research in the island of Aitu (Southern Cook Islands).

We asked our usual question of one participant: “Have you heard of TB/maki maro? He said, ‘You’ve got the right man. I was a tuberculosis”. At around age nine or 10 years, he developed pains in his chest when he breathed and became very skinny. He had to leave school and spend nearly a year in isolation in a room at the hospital. In those days, it was situated where the doctor’s residence is now... He explained that he was “B grade TB" so he did not have to be sent down the road near the lepers where the worst “A” cases were isolated... He did not remember very much about his treatment, except taking "a spoon of malt, it tasted like fish oil,
“everyday”, but he recalled the long days, the kindly nurses, and feeling sad and lonely, especially in the evenings when he would think of his parents and Grandma having their meal without him. The patients were not allowed visitors (2012, p.54-55).

For Ta’i (Case study 2) the stigma experienced by people with diabetes is closely tied to their judgment relating to food choices at public events. The account below also echoes earlier sentiments in this chapter about negative relationships between diabetics and doctors. A constraint to confidentiality in small places also features.

Evelyn: How did you feel when you found out that you had diabetes?
Ta’i: Well, at that time there was no shock, there was nothing, but after that being able to access information and then I sort of thought “Oh just as well I had got to the doctor early otherwise I would have lost an arm” and then you read about other people, suffering from things, so it was scary. I think there is still a bit of stigma involved in that you are scared to tell people that you are diabetic because, probably because they were scared of people telling you in public, don’t do that, don’t eat that, and there’s no confidentiality sometimes. I mean some people, I mean I don’t care now what people say if you are diabetics, that’s their problem, but a lot of people still sit back and I want to eat what I want to eat and I don’t want people telling me what to eat, who cares if I am a diabetic?

The narrative of Ta’i was also selected for its ability to bring together the complex interactions at play within the TB, diabetes and transnationalism syndemic. The complexities of the studying this syndemic with Cook Islanders include shifting perceptions of the body and health, obstacles to health services locally and transnationally, socio-economic and cultural relationships with food, and stigma. These interactions form a dense contingent network of conditions which compound the overall health vulnerability of Cook Islanders. I believe it also creates an environment where the clustering of TB and diabetes in the Cook Islands population is a threat now and in the future.

Summary

The personal expressions of TB and diabetes in this chapter highlight the biological and structural vulnerabilities of some of the Cook Islanders in this study. The patterns and meanings of the complete interview material across all interview locations elucidated key areas of relevance for health planning and promotion related to these conditions. These
areas of relevance, or key connecting pathways within the syndemic include issues relating to isolation from health services, the centrality and cultural specificity of food for Cook Islanders and new situations where stigma exists. It has also been demonstrated that each of these areas are interdependent, and that the connective mechanism of a syndemic is at play for Cook Islanders with TB and diabetes. The narratives in this chapter also build upon the case studies in the previous chapter by elevating the discussion to align with recent literature in this field. Overall, the narratives in this chapter bring forward the idea that Cook Islanders across the transnational social field are susceptible to exogenous factors which in turn exacerbate their experiences of disease.
CHAPTER SEVEN

Transnationalism and health

This chapter concentrates on the issues of access to health care and the transnational strategies employed by people and governments in the provision of health services for Cook Islanders. This section threads together the argument that health services for the Cook Islands population are dependent upon health service availability and transnational relationships and behaviours. “Feel the pain, get on the plane” is an often cited rhyme which refers to Cook Islanders' preference for health services in New Zealand. It also epitomises the pejorative view some Cook islanders have of their local health services. The frequency with which this idiom was repeated suggested to me that it has become normal to seek health care in New Zealand as a preference. However, the application of a syndemic framework in this context suggests a different scenario whereby harmful social conditions in New Zealand correspond to “get on the plane and then feel the pain”. The centrality of transnationalism within the TB and diabetes syndemic suggests that an alternative scenario exists: If Cook Islanders have always perceived New Zealand to be the place where ‘health’ is sought, the TB and diabetes syndemic highlights that this may actually be misinformed.

Included in this chapter are the transnational behaviours of inter-island or international movement of Cook Islanders in seeking health services in other places and maintaining economic, family and cultural ties to people across borders. Transnational behaviours include both the tangible and less tangible aspects of Cook Islanders’ transnational lives. The diverse interactions between transnational behaviours and the TB and diabetes syndemic indicate that the reach of social and health services constrained within nation state boundaries may not be adequate to alleviate the incidence and threat of the syndemic for Cook Islanders. The collaboration of health services pertaining to TB and diabetes in New Zealand and the Cook Islands is necessary in order to minimise the risks and future threats of the syndemic.

Transnationalism is useful because it points to the existence of a particular kind of social field with inherent characteristics that set it apart from other social fields of interaction that emerge as a result of regional interaction (Hoem 2009, p.191).
According to Hoem (2009) transnationalism is useful for identifying the idiosyncrasies of a group of people, and in a similar way, Mendenhall (2012) argues that syndemics provide a route to understanding the subtle particularities with each population. In this research the accounts of accessing health services across the transnational social field were common enough in regards to both TB and diabetes that it became obvious that for Cook Islanders, transnationalism is indeed a characteristic of health within the Cook Islands population. To understand this characteristic, it is important to distinguish the different threads of transnationalism which are operating within this syndemic.

Dimensions to the transnationalism and health relationship

Transnationalism has produced different types of livelihoods for Cook Islanders in the Cook Islands and New Zealand. In respect to TB and diabetes, the importance of nutrition in the face of economic hardship (Tu), household instability as a result of high levels of mobility (Rangi) and changing food behaviours (Kiri) are all examples of how transnationalism has altered food practices, constrained healthier choices and impacted upon health. The transnational health services of Cook Islanders are also shaped by New Zealand and development organisations such as the WHO and SPC. The priorities of organisations such as the WHO commonly set the agenda of health and development in the Cook Islands. Part of the overarching structures of the health systems between islands and nations is also the flow of medical equipment, pharmaceuticals and health professionals. Also feeding into this transnationalism are health demoting trade agreements (Kiloe 2009). In combination these different dimensions of transnationalism construct a particular social field which Cook Islanders engage with in an attempt to uncover different health, lifestyle, educational and employment opportunities inter-island and inter-nation. This research sheds light on experiences of fractured social and health support and stress, which as an outcome of transnationalism negatively contributes to and exacerbates the experiences of TB and diabetes.

For participants in New Zealand and the Cook Islands, the perception among the participants was that access to better health for themselves and their family was possible via moving to New Zealand. This research demonstrates that better health cannot be assumed to be a consequence of migration (Dunsford et al. 2011). One notable force, especially among the participants in New Zealand was Graves and Graves’ (1984) concept
of the “stress of adaptation”. Among the participants, this “stress of adaptation” was told through stories involving the physical stress of moving, finding accommodation, employment and navigating different social services. Cook Islanders under these conditions may also enter into transnational Cook Islands communities where similar experiences are present. In this study, the stress of adaptation of Cook Islanders living in New Zealand was observed to be part of the issue of household overcrowding. While the behaviour of allowing relatives to stay can be viewed as a cultural response to high levels of mobility, it is undeniably stressful for the people living in crowded situations. The stress of this environment in itself compounds other health conditions and can further constrain healthy choices and increase risk of infection from respiratory diseases (Baker et al. 2000; Baker et al. 2008). The close proximity of many Cook Islanders living in one place can also foster what Farmer (2000) refers to as “injurious social connections”. These injurious social connections are tied to the stress of adapting to a new way of life in New Zealand.

**Transnationalism and stress**

The entry into understanding the relationship between participation in transnational livelihoods and stress can be guided by The Tokelau Island Migrant Study. This study, which was also multi-sited in design and centred on the effects of movement between places and their impact on health is a useful starting point for theorising about different types of biophysiologic, environmental and psychosocial factors at play within the TB, diabetes and transnationalism syndemic. According to Kasl and Berkman, whose research interests also include migration and health:

> The Tokelau study remains a magnificent effort among migration studies. Beyond doubt, it illustrates some of the changes that accompany this kind of migration, primarily those relating to diet and physical activity (1983, p.86).

Indeed, The Tokelau Island Migrant Study is a useful historical study. The study, which explored the long-term health effects of migration from a tropical and subsistence life-style to an urbanised Western life-style included a range of health measurements recorded within a longitudinal study with ‘before’ and ‘after’ migrants in Tokelau and New Zealand (Salmond et al. 1989). One important component of this study which ties together the notions of stress, transnationalism and health was enquiry into the relationship between blood pressure and migration. The hypothesis of this study was that blood pressures
between the “home” and “away” populations should reflect “the experience of migration and its attendant changes and dislocations” (Salmond et al. 1989, p.39). The pathways identified in the study to higher levels of blood pressure among Tokelau migrants (particularly men) included changes in dietary composition and increases in weight as a result of total energy intake being higher in Western settings (Beaglehole et al. 1978) and psychosocial stress associated with dissonance which refers to the “conflicts between assimilation and private value systems” (Salmond et al. 1989, p.49).

In a separate paper, Salmond et al. provides a discussion of these pathways:

On the face of it, Tokelauans migrating from their isolated and slow-paced traditional environment are likely to be bombarded with the potential stresses of modern urban life on their migration to metropolitan New Zealand. It has been shown that Tokelau migrants who tended to interact more with New Zealanders and their way of life showed significantly higher blood pressures than did those whose interaction patterns tended to emphasise Tokelauan contacts... While these findings suggest that increased body mass, as well as the aging of the migrant population, may account for a large share of the heightened blood pressures among this group, it is likely that the cumulative effects of the stresses of migration and the urban experience have contributed their share to increased blood pressure among New Zealand Tokelauans (1985, p.299).

The pathways that Salmond et al. (1985) describe are the inseparable factors of personal and community interaction, food and body mass, ageing and blood pressure. Working through these factors are the ‘stresses of modern urban life’. Similar interactions were found to exist for one family in Glen Innes within this study (Case study 5). The account below describes the difficulty of finding reliable information and the different types of knowledge which are sourced from those in close proximity. It is the story of how parents found a cheaper alternative remedy for their son’s asthma when they noted a change in the frequency of their son’s asthma, which could have been attributed to age or change in environment. In a subsequent interview Rangi talked about their journey to becoming non-smokers, which would have also had environmental and health benefits for those living inside the house. In this short piece, there is a strong belief that this ‘cure’ helped them in the past and would also be used in the future if an attack occurred. Surrounding this quote are ideas of access and availability to the different ‘cures’ and the proximity of the advice of
a cousin. The path to this potentially harmful piece of information was adopted because it was less expensive and more readily available (Macpherson & Macpherson 1990).

Rangi’s wife: He used to be a bronchiolitis is, bronchiolitis, and asthmatic, asthmatic but now he is over that.
Rangi: It’s been a while.
Rangi’s wife: Since he was four years old, he’s my, our cousin, gave us something to cure that. It was only a sprite.
Evelyn: Sprite?
Rangi’s wife: you know the sprite, she just told us to give him that, when he started to, so we gave him when he started now.
Evelyn: Just lemonade?
Rangi’s wife: Yeah, that’s flat. Not in the fridge. Yeah four years, he was only four years old... The ventolin, we don’t use that anymore. But now he is over that. But we know when he comes back, when he plays a lot, plays and sweat a lot, that’s when it starts coming back. And also, weather changing.

Kasl and Berkman argue that knowledge of health and welfare for migrants may not increase over time and that there is a need to pay more attention to “the dynamics of the social and personal forces that precipitate changes in health habits and exposure” (1983, p.86). For Cook Islanders, health and social services exist at different scales, from small informal services in an outer island, to sophisticated services in metropolitan cities. To date, only experience or advice from other people can prepare Cook Islanders for these starkly different health service access situations, and as Kasl and Berkman (1983) argue we cannot assume that knowledge of social and health services in a new country of residence will automatically increase over time. In each research setting there were examples of participants not having the knowledge to successfully engage with the health system. In the narrative below, Rangi shares some of his transitional experiences between Rarotonga and Auckland. It is clear in this piece, that being accorded New Zealand citizenship does not equip some Cook Islanders with the knowledge and tools to set up a healthy life in New Zealand.

Evelyn: What do you think could have made it easier for young families coming from Rarotonga to move here? You said that you were interested in giving your children a better education and more opportunities so what could have made that process smoother for you in terms of keeping your children healthy, having a good home, all of that stuff?
Rangi: I think, I don’t know, but for myself through my experience I think it’s better if you are going to move over here, to prepare first, to think carefully before you make some plans, not just for one
person but for friends and all other people. They can help, so if we have a sort of a system that I want to move to New Zealand or Australia you just go to those people and ask questions, what can we do, when we arrive there, what are the things that we need to know, all those things, I think that will prepare us for coming over here.

Evelyn: So at the moment when you decide to make that journey, you just turn up in someone’s house and ask them?

Rangi: Yes.

Evelyn: So if they don’t have quite the right information you might go down the wrong road.

Rangi: That’s right, yes, because from my experience this is something that’s mouth to mouth, you go over there, blah, blah, we will help you, but that didn’t happen when we got here. So we had to make, even the biggest part is, because what I mean is like because where we come from we don’t worry about monies and all that but when we come over here we found out that everything is just to do about money. So we are not really educated for that so it makes it really hard, with no support from our family, it was really difficult for us. But if we had some place, like a centre, like a family centre or some sort of organisation where we can go when a young family wants to move somewhere they can go and ask for help. You see for now, if I want to move to Australia I don’t know what to expect in Australia, you know what I am trying to say. I don’t know what I am going to need over there, what they expect of me, what is the first thing I am going to do, those kinds of things.

Evelyn: Right, that’s important information.

Rangi: Yes, that’s right.

Evelyn: And do you talk about how hard it’s been for you over here with other people that have moved from Cook Islands or is it something that you just talk to your wife about?

Rangi: No, I talk to anyone I know that asks questions. If someone asks me questions I share my experience.

Evelyn: When I talk to families in Rarotonga no one really talks about the hardship that families go through over here, even basic things like the climate and affording warm clothes for your children, little things like that.

Rangi: No, I think really coming to terms with those little things wouldn’t be happening if we really know what we are going through, what we are expecting when we come over here. So at least if we know what we are expecting to come over here, what the resources are, what type of help we can get, even the health, the financial, all those little things, I think we would be more prepared. One of the big things I found out is that because we are freely lived on there and our life is and so when we come over here everything is cheap because we are not really educated, you know, top dollar, only five hundred a month, and that’s really cheap for us but we are not really educated on financial for the future and that’s another
way of putting people in debt. When they get themselves in that situation that’s what’s going to happen, we can’t afford to buy that much food to feed our family, we can’t you know, we can’t afford the warm clothes and we can’t and that’s let us down.

Evelyn: So how did you guys find going to the general hospital and Starship Hospital coming from Rarotonga?

Rangi: That was through sitting with mum and dad and through that we learnt to try and memorise the roads, not the names but the way, to go there, and just going and asking. We made a mistake and we learn from that. That’s how basically I think we learn, by making mistakes. Yes, we learnt from that.

In this narrative, Rangi interprets the question of how he found the hospital and children’s hospital in Auckland in a literal sense, relaying his mental mapping of the transport route leading to location of these services. However, Rangi’s reference to learning from mistakes suggests that at times, Rangi and his family were under considerable stress navigating larger and more complex health and social services. It also signals that the fracturing of personal and public support systems occurs across the Cook Islands transnational social field. The quote alludes to Rangi being unprepared for life in New Zealand. The quote mentions that hardship experienced by Cook Islanders in New Zealand is not spoken about in the Cook Islands, and is still promoted as a place of better opportunities. Rangi believes that Cook Islanders should have a “place” to go to where issues on increased costs of clothing and food can be discussed. I believe that the issues raised by Rangi in this quote demonstrate some of the reasons behind the unstable vulnerable conditions for Cook Islanders in New Zealand, and particular pathways within the TB, diabetes and transnationalism syndemic. These pathways relate predominantly to lack of information and financial security of unprepared young Cook Islands family migrants to New Zealand.

**Transnationalism, health and support systems**

Cook Islanders rarely move as individuals over a long distance and there is an assumption that kin networks are health promoting and health facilitating. Cook Islands extended families and community networks can be health promoting, however, some people remain isolated from families which can implicate access to health services. The diary entry below describes the first time I encountered isolation from family support systems:
Research diary entry 17th August 2011

Her right leg is bothering her, ‘the bones’ she said. I asked if it was arthritis but Annabelle didn’t know. She told me how a notice came to go to the hospital in Auckland to see the ‘bone doctor’ but she threw it away. “I have no way to get there. Never mind Evelyn, maybe it is just the old age”. I asked if I could see the letter, but she no longer had it. I asked Anabelle to make sure she kept these letters to show me and that I can always take her to her appointments. She understood that she could arrange for someone to take her ‘through the health’ but she forgot to say. I remembered that her children in NZ did shift work, however, it still seems unusual for her not to have someone in her church or family network to take her. This highlights that although Cook Islanders have “kin networks” we cannot assume that they are reliable with regards to accessing health services. I asked Anabelle about how she goes to her diabetes clinics. She said that she caught a taxi there and that she always managed to find someone to bring her home. It would be good to make this journey with her. I asked her about how much the taxi cost. Anabelle could tell me exactly the amount of the taxi and her medication. This told me that she is well organised.

The accounts of Rangi and Anabelle illustrate that transnationalism does not directly relate to seamless health access in two countries and that isolation from health services may be a result of broken networks. For example, the narratives of the participants illustrate that although transnational communities can be protective (Dunsford et al. 2011) they cannot be relied upon to always deliver support or knowledge in terms of health. In addition, Cook Islanders transnational behaviours also come up against real barriers for return migration to the Cook Islands if certain health services needed are only available in New Zealand. This challenges the commonly held assumption of many Cook Islanders that they will be able to move freely back and forth from the Cook Islands and New Zealand. The dream of many of those who came in the 1970s is to return to the islands for retirement. Over the years, participants such as Tu and John were motivated by the notion that one day, their hard work in the metropolitan cities would be rewarded with a peaceful retirement on their ‘home’ island. However, for the participants on renal dialysis, their ability to move back to the Cook Islands is now constrained by their reliance upon New Zealand services. It appears that mobility between the Cook Islands and New Zealand is obstructed by their health for not just themselves but also their families who have taken on a leading role in their care. Their health has changed their family’s mobility trajectory.
John: It was so good when I went, I didn’t feel like coming back at all... I have nothing against NZ, NZ has been good to me. But it’s my time to go home. But I can’t go home because of my health. I’m sure if we had the dialysis machine back home I wouldn’t be here. I would be in Rarotonga. ...Even today my heart is still back home. I’m only here because of my health. As soon as I get my transplant BOOM I’m back there... I know two of my mates around here we go to Carrington, but I have been moved to Green Lane. And when we dialyse at the same time, that’s what we all talk about. Being home. We always talk about being home... I’m disappointed with our government. All they are doing is sending us over here. They don’t want the cost to run this or run that you know for doctors and so they prefer to send them over here and it’s out of their hands. That’s what they do... For the people on dialysis, a lot of our people want to go back there. For example, I can only go there for three days. I would love to go there for two weeks or a month. But we are not able to. But Samoa, they have their own dialysis. But we don’t have any. They always come up with an excuse. There’s not enough water. It will cost to run the place. Of course it will cost to run the place! Technology things and all this, and all this and it’s easier for them. This is from one of our politicians, what he said “It’s easier for them to send you people over here”.

As the cohort of Cook Islanders who worked in New Zealand during the ‘60s and ‘70s ages, different relationships will need to emerge between New Zealand and the Cook Islands to manage their health and social welfare needs across the transnational social field.

The decision to seek health services in New Zealand was a determining mobility force for most of the participants that I interviewed in New Zealand (Koteka-Wright 2007). In some cases it was a family member who needed the services, but the participants had stayed on in a more long term capacity (Case study 4). In Rangi’s case it is obvious how seeking health services across international boundaries by a family member can spark a chain of health related, transnational movements over multiple generations. The case studies have revealed children accompanying parents and parents accompanying children on these journeys. Within other case studies transnational health service access was also seen to correspond to further movement to take a deceased family member back to islands, or to find secure support networks in other locations. It is also clear that these health service access movements also alter housing arrangements, which in turn can directly impact upon health and subsequent health service access. It is unfortunate that the accounts of the participants suggest that these transnational movements for health are not supported with
adequate information about social structures and health systems in New Zealand. Responses to Cook Islanders seeking health services are nation specific, and information about these health services are acquired by Cook Islanders as they navigate them. The quote below talks about the 28 day constraints experienced by elderly Cook Islanders in New Zealand who rely on the pension as their main income. It illustrates Anabelle’s navigation of Cook Islands mobility within the constraints of depending upon the social services in New Zealand.

Anabelle: In 2004 I went to take his (husband’s) headstone.
Evelyn: Right and how long did you stay when you went back to Mauke, how long did you stay there?
Anabelle: Oh only for you know, because of my benefit, I was only maybe 20 days, and I, and I come back within 2 weeks.
Evelyn: Right.
Anabelle: The working and income allow me to go over there for, don’t be after 28 days, before 28 days come back to New Zealand. You understand me? So I come back within 20 days.

Transnational health seeking behaviours require knowledge of multiple health and social service systems. Moreover, the person needs to be able to anticipate gaps and connections in the health services across transnational space. There were some participants who in their interviews conveyed a sophisticated understanding of how to access health services between New Zealand and the Cook Islands. John Lindsay in Case study 1 is one example. He appeared to have the finances and the knowledge to leverage the health services to his benefit in more than one country. He understood where the gaps existed and could convey his sense of disappointment with the Cook Islands government for not planning for Cook Islanders to live and dialyse in Rarotonga. It appears that although Cook Islanders citizenship in New Zealand was perceived by many of the participants to map directly onto the health and social services in both countries there are systems, protocols and procedures that carve out the different types of mobilities permitted for Cook Islanders. There are ‘rules of engagement’ with the Cook Islands transnational social field with regards to health, housing, education and social service access. To actively change the unequal distribution of health conditions of Cook Islanders in New Zealand, more attention needs to be placed upon promoting an awareness of how the health and social systems operate in both places. Unfortunately, as this section has demonstrated, the filtering of this information through

35 Similarly Case study 1 looks at the constraints for mobility when dependency upon dialysis is a factor.
official and personal networks needs to be strengthened, particularly in the situation of Cook Islanders in New Zealand.

The realities of the TB, diabetes and transnationalism syndemic

This research builds upon existing literature where conditions of social and economic disadvantage disproportionately impact upon the health of both Cook Islanders and the wider Pacific people’s population in New Zealand (Davis 1984; Tukuitonga and Finau 1997; Wright and Hornblow 2008). Internationally, other authors have commented on the need to resist viewing disease as single entities (Freudenberg et al. 2006; Singer and Clair 2003). Through syndemic analysis I argue it is also possible to explore the patterns of diseases across a transnational social field. As Kasl and Berkman argue:

Instead of asking, "Is there more to it (health consequences of migration) than the effect of known risk factors?" we should pay more attention to the process itself (health habits, environmental exposure), so that we may understand the paths that lead to the changes of risk factors (1983, p.86).

In this study, the transnational behaviours of Cook Islanders are seen as not just the solution to health disadvantages but also a serious threat. Nearly 20 years ago Davis discussed health in New Zealand by arguing that:

... there is something further about the cultural, social and economic circumstances of ethnic minorities over and above their social class position that must be called into account to explain their special health disadvantages (1984, p.923)

Transnational behaviours set up via historical and colonial relationships may also be the key to unlocking the reason behind historical health disadvantages. By dismantling the syndemic ties between TB and diabetes and bringing forth how this is expressed in people’s homes and their bodies, the force of transnationalism becomes clear. In this way, it is not only the movement of Cook Islanders which is significant, but also “the dynamics of the social and personal forces that precipitate changes in health habits and exposure” (Kasl and Berkman 1983, p.86) that accompany Cook Islanders as they navigate the transnational social field. I argue that for Cook Islanders, socio-economic “cumulative disadvantage over a life course” (Everett 2009, p.9) has played a critical role in the TB, diabetes and transnationalism syndemic. Furthermore, one of the key contributions syndemic analysis offers researchers is the ability to delve deeply into key areas of interest whilst keeping in
sight the significance of the pathways between transnationalism and health. As Spoonley et al. assert “In the face of such impoverishment, Pacific people seek to deploy their human and social resources strategically across various locations” (2003, p.40).

Although the diseases in this syndemic are typically split between communicable and non-communicable categories, the transnational orientation of this study emphasised how contagious/communicable mechanisms operate across disease categories in the Cook Islands population. The mechanisms, made up of particular behaviours, were common in houses across the transnational social field. The delayed doctor visits is one example, and as the previous chapter has illustrated, Cook Islanders generally present later with more serious disease at health services in New Zealand (Tukuitonga and Finau 1997 for a discussion on Pacific peoples delays in seeking health services). Emphasis is also being placed on encouraging more Cook Islanders in the Cook Islands to use primary health services instead of waiting until a serious health issues leads them to the hospital. The threat of delayed treatment seeking behaviour within the TB, diabetes and transnationalism syndemic is that it can result in increased associated health conditions such as renal failure for diabetes patients and heighten the risk of spreading TB. Furthermore, diabetes, when not managed properly, can reactivate latent TB and compound issues of diagnosis if both diseases are present (Restrepo et al. 2006). The syndemic framework in this thesis highlights how complications spiral out of control over time if a diagnosis and treatment is not sought in a timely fashion. Contributing to and exacerbating the connection between TB and diabetes are transnational behaviours, gaps in health systems and cultural responses to seeking health services.

In the health and development literature, poor access to health services and inequalities in health is a dominant theme (Cameron and Harrison 1997; Hill and Calder 2000; Malcolm 1996; Simmons 1996; Tukuitonga and Finau 1997). Access to and low use of primary health services can be constrained by financial barriers (Malcolm 1996), not knowing how to access services and manifestations of stigma. In the Cook Islands, people may appear to have a less complicated route to primary health services at either outpatient clinics or at the local hospital. The scale of public health services in the Cook Islands works in favour of the community in that it is easily accessible and that PHNs and doctors are active members of their communities. Access to information can be either formal or very informal depending
upon need and the relationship a person has with the provider. Cook Islanders returning from New Zealand to the Cook Islands either permanently or temporarily do not appear to have difficulty understanding the health systems in the islands. One of the reasons may be that it is common for PHNs to chat with community members outside of schools, shops or village events about health concerns and more formal information is available in clinics, over the radio or through public health campaigns in the newspaper. However, the scale of the public health system in the Cook Islands also works less favourably for some participants who delay seeking health services because of fear of reprisal and repercussions (Dunsford et al. 2011; Hill and Calder 2000; Singer and Clair 2003).

In a study of ethnic disparities in mortality in the 1990s in New Zealand Blakely et al. argue that certain lifestyle risk factors point to the unequal distribution of mortality between Maori and non-Maori populations (2005). In this discussion the authors argue that alongside risk factors such as smoking, the Maori population was also disadvantaged in terms of the health impacts of social upheaval, stress, and institutional, interpersonal and internalised discrimination. Blakely et al. state:

There are many possible explanations for this pattern (diverging ethnic mortality trends)...structural, risk factors, health services and discrimination. These explanations are not mutually exclusive, rather they are layered and highly likely to interact with each other (2005, p.2244).

Interactions and mutual inclusivity of structural and cultural risk factors is evident in the relationship between inadequate housing, poverty and transnationalism and the resulting conditions associated with household overcrowding (Cheer et al. 2002; Crump et al. 2001; Milne and Kearns 1999). Research by Baker et al. (2000) identified the relationship in New Zealand between inadequate housing and the increased risk of TBD and latent TB and an increase in associated health conditions. This thesis contributes to the literature by thinking through the negative contribution transnationalism makes on overcrowded and inadequate housing situations. For example, before thinking about the relationship between household overcrowding and TB transmission, I argue that it is necessary to understand the order of events and forces which have resulted in overcrowded conditions. This research has uncovered that health vulnerability increases when people have a marginal relationship with housing organisations, house owners or other people in the household. For the participants in this study with TB and diabetes, particularly in New Zealand, accounts of
housing issues were connected to the stress of too many people living together, lack of privacy and conflict in the household. In the TB, diabetes and transnationalism syndemic, the issue of ‘housing’ for Cook Islanders adds environmental, biological, structural, cultural and personal relationship dimensions to the problem. According to Nichter (2008) household boundaries are permeable and their membership is fluid. In this way, homes and households cannot be conceived as fixed physical spaces; instead they are conceived as active sites of many overlapping pathways.

In the Cook Islands, home and family life is more visible not only to health practitioners but also to village and community members. The clinics, hospital and mobile Public Health Nurses are familiar, affordable and often form part of a social experience. A key observation during this study was that this does not translate well to New Zealand society. The fences, walls, doors and shut windows in Auckland and Porirua were a physical metaphor for the isolation the participants felt from the health system in New Zealand. The lack of anonymity in the Cook Islands and the frequency in which I would overhear people discussing a family member’s health concerns with clinicians, in combination with the cultural significance of village clinics, conveyed a sense of openness and community awareness about health in Rarotonga and Aitutaki. The flip side to this openness and community awareness is that confidentiality is difficult to protect and as Figure 10 displays, sometimes no attempts are made to conceal the health issues village members are facing. Nevertheless, this research views Public Health Nurses treating both TB and diabetes as very important features of the health systems operating in the Cook Islands and New Zealand.

36 Treatment for TB by the Public Health Nurses includes DOTs, diagnostic testing and accompanying patients to clinics. Treatment for diabetes by the Public Health Nurses includes blood sugar level tests, treatment for associated conditions such as skin ulcerations and arranging appointments with nutritionists, and podiatrists.
Accompanying Annabelle to the chest clinic

During the field research stage I accompanied Annabelle to a chest clinic so that I could observe the interaction of a TB patient (who also has diabetes) with the New Zealand health system. This observation exercise at the chest clinic revealed the process of treating Annabelle was comparatively sophisticated yet impersonal. It was also obvious that the scale of the facility and expertise of the clinicians did not help avert Anabelle’s fears nor provide her with more health service access confidence.

*Research diary entry June 24th 2010 Green Lane Respiratory clinic*

The first thing I noticed about the Green Lane outpatient’s clinic was that it resembled an airport more than a hospital. It was clean, modern and without the usual smell of a hospital. By 10 am in the morning it was already very full of people. The respiratory clinic is on the 1st floor up an elevator. It took several signs in the lobby for me understand exactly how to get there. For people with English as a second language navigating this space would be a real challenge. The people at the front desk giving directions were very busy. The cost and complicated entry procedure for cars is another potential barrier.

As I attempted to walk in the shoes of the Cook Islander with TB seeking treatment at an outpatient clinic my initial observation was how overwhelmingly unfamiliar the environment was. The scale of the clinic, on several levels, was sleek and well organised to the point of not resembling our usual ideas of clinics or hospitals. There was very little health
promotion on any of the walls. Doctors, nurses and receptionists were in plain clothes and there was not the usual smell of disinfectant. Observing the daily routines in hospitals and clinics in Rarotonga and several of the outer islands throughout my life alerted me to how different this ‘clinic’ was to a Cook Islander who was used to attending clinics in smaller premises, where you were likely to have a relationship with either someone working there or someone also attending. The location of the Green Lane Outpatient clinic would have also been an obstacle for people without a car or the means to travel by bus.

*Research diary entry June 24th 2010 Green Lane Respiratory clinic continued…*

In the waiting room, two adjacent desks served Dermatology and Respiratory. You could not really establish who was here for Dermatology and who was here for Respiratory just by looking at them. Maybe this was the point?

During this visit I was attuned to the medical explanations and organisations of health services. Not only did it appear to be a strange juxtaposition of health conditions, but there were no translations or explanations offered alongside of the signs. For a person with limited exposure to anatomical or medical language, navigating this space would be very difficult. This observation was later confirmed by Anabelle’s query of the signage in the clinic.

*Research diary entry June 24th 2010 Green Lane Respiratory clinic continued…*

Anabelle arrived around 10.20am with her health assistant. She had so many clothes on. She was finding it hard to walk even though she had a stick. It took a while for her to recognise me, but she seemed relieved that I was there. I accompanied her to get weighed in by the nurse. I helped her undress (take two coats off). She seemed very comfortable with me doing this for her. I was surprised at how little she weighed. After this we went and sat back down and had a chat. I had to reexplain to her why I was here. She finds it difficult to understand what I am studying; she even suggested to me that I seem smart enough to be a nurse. Anabelle surprisingly asked me “what does that word mean over there” pointing to the ‘respiratory’ sign. Further along the wall, a similar sign offered a translation of ‘lungs’, however this one did not. I indicated where it was on the body. She seemed confused, leading me to once again reconsider if she had extra pulmonary TB.

Anabelle seemed relieved once she could recall our connection and previous conversations. Although Anabelle struggled to understand why I was interested in visiting the clinic with her, she quickly allowed herself to establish trust with me, given that although our
relationship was new, it was nonetheless something familiar in this anonymous environment. Contained within this quote is a snippet of both Anabelle’s and my struggle to determine if Anabelle fell under the category of pulmonary TB or extra pulmonary TB. Previously, Anabelle had spoken to me about a persistent cough leading her to the doctor, as well as about being in isolation in the hospital during treatment. However, there was a large nodule on Anabelle’s neck, which she always pointed to when she spoke about TB.

Later on, when called into the doctor’s room, the miscommunication between her appointment and her health condition continued. There was confusion because the first question the doctor in the respiratory clinic asked was regarding pain in Anabelle’s legs. At this point, I realised that Anabelle had had both extra pulmonary and pulmonary TB and that the respiratory clinic served both areas of TB treatment. The scrutinising and sarcastic tone used by the doctor prompted Anabelle to tightly clutch to my hand. I sensed that she was both frightened and confused throughout the consultation.

Research diary entry June 24th 2010 Green Lane Respiratory clinic continued…

At around 11.00 we were called in to see the doctor. The doctor was in his late 50s. Anabelle took hold of my hand at this stage. She held it very tightly, making me think that she felt a little vulnerable. On our walk to his office, she mentioned that she saw this doctor last time. I briefly explained who I was to the doctor; he didn’t seem to mind me being there. I think he could sense that I was offering Anabelle some support. “Oh so you are playing minder today?” The first thing the doctor asked Anabelle, was “where is the pain in your joints?” Anabelle stroked her thigh to indicate where it was but had no word to explain it. He asked, “Is it your knee or your hip?” Anabelle looked at me and said “Evelyn?” and stroked her leg again. I felt as though I let her down because I could not ask her in Maori or translate the doctor’s question in Maori. In a rather patronising tone he asked Anabelle “how are you doing?” Anabelle said, “Yes, how am I doing?” this was followed by “I don’t know, that’s why I am asking you”. I found this rather upsetting. She said “about these? These lumps?” “Yes” said the doctor, “I know about those lumps I will look at them in a minute”.

The remaining notes from this diary entry point to the importance of language and misunderstanding whilst navigating unfamiliar health services.

Research diary entry June 24th 2010 Green Lane Respiratory clinic continued…

The theme of misunderstanding and language was really prevalent today. Signage, doctor’s language, personal knowledge of the body
and disease are all potential points of misunderstanding. The rhetorical questions used by the doctor added to this misunderstanding. His manner was inappropriate for dealing with someone where English is his or her second language. Anabelle was noticeably more uneasy at the hospital than in her own home. She seemed very vulnerable to me that day.

The visit with Anabelle to the chest clinic was followed up with two more interviews. As time went by and the TB treatment ended Anabelle told me that she had more energy to garden or sew. She also appeared happier. I asked if she had needed to visit the Auckland Hospital or the chest clinic again, and she told me that she only needed to attend the local diabetes clinic in Otara. She enjoyed these clinics because they were at the local shopping centre where she would often meet up with people she knew. On reflection of the time we spent together at the chest clinic I believe that her previous experiences of isolation at the Auckland hospital during TB treatment and the scale of the Green Lane Outpatients Clinic were the main contributors to her stress and vulnerability on this occasion.

**Syndemics and transnationalism**

The narratives and case studies in this thesis have told the stories of dense and contingent factors operating within the TB, diabetes and transnationalism syndemic. In particular, transnationalism has been presented as a main influencer of social, economic and health outcomes. Alongside both the contextual and lived realities of transnationalism for Cook Islanders are the distinctive threads which weave themselves in and out of the stories of the participants. I have attempted, in this final section of the chapter to visually present the key characteristics of the TB, diabetes and transnationalism syndemic for the Cook Islands population. For other authors in the field of syndemics, being able to name the syndemic with the use of an acronym signals a definitive statement about its existence (Singer 1996; Mendenhall 2012). However, my ability to make definitive statements rests with my ability to conceptually and visually present how the syndemic is being sustained. In a similar fashion to Lawrence (2007), I uncovered multiple ‘layers of disadvantage’ among the Cook Islanders included in this study and the use of a syndemic framework has allowed these layers to be interrogated against the literature and observations in a way that can bring forth the connections.
There are other authors who believe that conceptual tools can assist in the visualisation of how syndemics operate within a transnational social field and population. Recently, Park et al. stated that:

One of the conceptual problems we face in our current research project, ‘Transnational Pacific Health through the Lens of Tuberculosis’ is understanding and theorising multiple, interconnected, lineal and lateral linkages which are part of contemporary patterns of tuberculosis (TB), both in New Zealand and the wider Pacific region (2011, p.6).

To counter this problem of conceptualisation the authors suggest that a ‘whakapapa’ or mind map may “provide a coordinating framework for social theories of complexity” (ibid). For example, the authors argue that a mind mapping process allows understandings to be organised from simplistic through to complex sets of relationships between nonhuman species (in this case bacteria), social conditions, socially responsive physical environments and mobilities of people, things and ideas (Park et al. 2011).
Figure 11 demonstrates that this thesis views context and person as inseparable. The physical, emotional, political and cultural strands of this thesis are symbolic of a physical body which is within transnational space and constantly engaging in relationships with other people. In this way, the connections between the research context, participants and guiding concepts synergise in the same manner as the complexities of people’s experiences of TB and diabetes. In Figure 11 it also becomes clear that there is causality at play in the TB, diabetes and transnationalism syndemic. For example, transnationalism forms the centre of the study, and provides a starting position to consider the interactions of other significant factors. In order to perform this study, the second layer illustrates that latent TB and high levels of diabetes must be a necessary condition of the population, which in this case is Cook Islanders. Latent TB is positioned as the key biological threat to the TB and diabetes syndemic, which because of transnational behaviours exists across island and national boundaries. Moving outwards from these points are the issues of food and housing as structural and cultural conditions which foster diabetes and TB. Overcrowding also features as both a risk for TB and diabetes and a consequence of transnationalism. The width of stigma in the diagram conveys that in its different manifestations, stigma appears to be operating at every level. The relationship between stigma and diagnosis is identified in the diagram as a very significant interaction, which, if addressed could counter this syndemic in the future (more in chapter eight). The overlapping conceptualisation of the TB, diabetes and transnationalism syndemic allowed and helped to create a definitive impression of the demonstrable factors which are synergistically sustaining the syndemic.
CHAPTER EIGHT
Conclusion: The contextual, conceptual and empirical layers of the research

Transnationalism is undeniably a factor in the Cook Islands TB and diabetes syndemic. Its force was apparent across the accounts of the participants in all study locations. This dimension also appeared to incorporate a range of socio-economic, cultural and political factors which intensify negative health outcomes. Exploring the connections between these different non-biological pathways in this study was facilitated by the lens of TB. Dunsford et al. similarly state:

Our use of TB as a window into Pacific health helps us better understand the relationships between Pacific people and the NZ health system over time and clearly illustrates themes that continue to resonate (2011, p.65).

I have attempted in this thesis to demonstrate that by using TB as a lens and syndemic theory as a guide through multi-sited research, that it is indeed possible to explore the role of transnationalism in health. This thesis rises to the challenge of exploring the dimension of transnationalism in health (Littleton and Park 2009; Dunsford et al. 2011) and the negative consequences of transnationalism (Levitt and Jaworski 2007). TB as a window in to a population such as Cook Islanders, whose realities are enmeshed in colonial and aid donor relationships, performed the important function of being able to dovetail into debates on social inequalities over time (Singer 2009). This thesis provides empirical evidence of Cook Islanders’ health as part of global health and development issues, in particular, the existence and threat of unequal burdens of communicable and non-communicable disease (Taylor et al. 2005). Moreover, this thesis contributes to the current research on TB and diabetes co-morbidity in the Western Pacific region (Viney et al. 2011) by advocating for an awareness and application of syndemic frameworks. In doing so, new pathways such as transnationalism could be uncovered to tie together TB and diabetes within other populations.

The application of a syndemic framework has strongly influenced the iterative processes of defining the nature and significance of TB, diabetes and transnationalism. I have carefully documented my process of working with a syndemic framework in a manner which deals
with the contextual interplay of political, historical, cultural and health factors in light of the research experience and research material collected. Beyond the overarching argument that transnationalism is a factor in this syndemic, other key findings which relate to the health of Cook Islanders have surfaced. In this chapter I wish to revisit the original research question in light of the analysis provided.

What are the relationships between TB, diabetes and transnationalism within the Cook Islands population?

In addition to a review of the main findings of the research, some additional anecdotal examples are used to highlight possible opportunities to action change in both the Cook Islands and New Zealand.

Summary of key findings

Fluid and bounded responses to health and transnationalism

This study advances research in the areas of health and migration studies by exploring the synergistic interactions which contribute to the unequal burden of disease across a transnational social field. The stories and accounts in this thesis have illuminated the assertion that “Everyday transnational practices are not neatly compartmentalised nor are their consequences” (Guarnizo 2003, p.669). I have demonstrated that the accounts in this thesis speak to both fluid and bounded experiences of Cook Islanders and health. The fluid responses have highlighted the positive linkages within the Cook Islands transnational social field, whilst the bounded responses have highlighted the gaps in health systems and the fractures in social structures. Included in these accounts are sentiments which relate to colonialism (Banks and McGregor 2011; Murray and Overton 2011; Spoonley et al. 2003; Teaiwa 2012) and the cultural characteristics (Hannerz 1996) of transnationalism. Cook Islanders embody a set of cultural practices which are strongly influenced by colonial history and contemporary international relationships with New Zealand. The stories in chapter five perform the role of untying the relationships which surround Cook Islanders’ experiences of health, and in doing so reveal how Cook Islanders occupy a complex space across nations and within multiple communities. As Hannerz argues, ideas of community and the nation are problematic when a population is inherently transnational:
The identities of Cook Islanders portrayed in this thesis are not static, but rather mutable in relation to particular experiences of health issues. The desires of Cook Islanders to seek different health service access or an alternative lifestyle also transcends island, atoll and nation boundaries. Simultaneously, the Cook Islands and New Zealand are imagined as places where participants would rather be for health and lifestyle reasons. In this research the interview participants also appeared to have different loyalties to either the New Zealand or Cook Islands ‘nation’ depending upon their health scenarios (or their health needs). The transnational writings of Burns-McGrath (2002) comment that transnationalism allows for flexible membership within an imagined community across nations. This thesis adds to her work with Samoans by illustrating that Cook Islanders simultaneously negotiate obligations and connections over time and through space. Working through the syndemic framework towards the associated health condition of renal failure illustrates this poignantly. The tragedies uncovered in this research are the accounts of coming to terms with the reality that retirement in the Cook Islands is hindered by dependency upon dialysis. The fluid and unbounded notions of Cook Islanders being able to freely move between the countries and strategically position themselves for better lives has not been a lived reality for many of the study participants. Instead, participants who were interviewed in New Zealand and the Cook Islands feel a great sense of disappointment that their New Zealand citizenship does not map directly onto better opportunities in either nation.

Reaching an understanding of the uneven health access for Cook Islanders was made possible by tracing the transnational social field and conducting multi-sited ethnographies. This thesis conveys a sense of unequal health and uneven health access (Nichter 2008) for some Cook Islanders. Making an assertion such as this raises questions about variations in health patterns of a population across nations and the selectivity and efficacy of the health care systems. In this thesis New Zealand is perceived to exert influence upon health service access variations in the Cook Islands. As Yuval-Davis describes:

While some borders in some states are constructed along natural delineating signs such as sea, a river or mountain chain, other borders have been constructed as a result of complex negotiations
between states, often not even the states directly concerned by the superpowers of the day (1999, p.124).

Cook Islanders in this research are demonstrated to navigate this array of borders, illuminating that transnational lives are not seamless across countries. This is explicitly evident in the concentration of prevention and treatment between Rarotonga and Auckland through flows of patients, specialists, and equipment, knowledge and partnership agreements. For Cook Islanders outside of these places the physical environment and social, political and economic factors create additional obstacles to seeking health services. Furthermore, health influencing agreements in the areas of trade, pharmaceuticals and complex and changing relationships between New Zealand, international development organisations and donor country recipients also affect the health for Cook Islanders. Negotiating these borders and dense networks of health services can be stressful, which when compounded with the stress of having TB and diabetes creates a situation where negative health outcomes are inevitable. In particular, this thesis has provided empirical evidence of the health implications of the stress associated with moving and the breaking down of social and cultural infrastructure.

Transnationalism introduces new sets of health service access behaviours and comparative expectations of health services. In this research, the event of diagnosis was used to explore how Cook Islanders with TB and diabetes engage with health professionals, health systems and their own identity. The case studies and narratives convey a preference for self-diagnosis because of a fear of belittlement (as form of self-stigmatisation) or avoiding diagnosis because prior health service experiences have changed their health service expectations (e.g. a preference to be seen by a ‘proper’ foreign doctor). These sentiments are a result of the Cook Islanders being able to make personal comparisons about health service access across the transnational social field. In this way, the transnational social field has altered health expectations for Cook Islanders. The voices of the participants also speak to the fragility and vulnerability of some Cook Islanders who delay diagnosis (both in the Cook Islands and New Zealand) and have complicating associated health conditions as a result. Delay in diagnosis presents real risks for increased and rapid onset of associated health conditions and higher transmission rates of TB (Hill and Calder 2000). In this thesis many of the barriers to delays in diagnosis have been illustrated. These include economic, social and political obstacles. To diminish these barriers for Cook Islanders, health policies
and research needs to extend beyond the nation state and increasingly recognise the needs of highly mobile people. While relationships between New Zealand and the Cook Islands and indeed development organisations in the area of health do exist, the reality for Cook Islanders is that they have to navigate place specific and nationally designed health systems in multiple countries. In this thesis I have also argued that the cultural and stigmatising experiences of participants amplifies deterrent behaviours (see below).

**Transnationalism, health and housing**

Within this thesis significant attention has been given to the relationships between population mobility, health and housing. Across the Cook Islands transnational social field there was evidence of how inadequate housing had exacerbated the experiences of TB and/or diabetes. It is important to note, that these relationships were place specific. For example, the health implications of a leaking cyclone shelter in Aitutaki were different from an overcrowded, two bedroom house in Glen Innes. Nevertheless, within the syndemic framework, particular demonstrable relationships were seen to exist across the transnational social field. First, the mobility of the Cook Islander population may lead to pressures upon housing and increase the health effects associated with overcrowding. Second, Cook Islanders’ housing is frequently related to family social structures. These structures can be health demoting, depending upon flows of information through these networks. Third, renting houses in New Zealand on limited wages or social service benefits may cause Cook Islanders to strategise the remaining funds available between other living costs. This can result in heating being forgone or cheap calorie dense and less healthy food being purchased. This finding aligns with the earlier research of Cheer et al. who, through interviewing, were able to substantiate that in New Zealand “healthy behaviours are ‘discounted’ in the expenditures of low-income households within the changing structural context of decision making generated by recent housing and other social policies” (2002, p.497). This study extends this finding by unravelling the ties between housing, food (nutrition), TB and diabetes. Ensuring adequate housing and adequate nutrition for Cook Islanders in both countries presents a possible opportunity to disrupt the TB and diabetes syndemic.
The Cook Islands transnational community, food, stress and stigma

Another significant dimension to the syndemic which is connected to housing and food behaviours are issues of cultural and individual identity. As Pollock states “A balanced meal has many dimensions in today’s world” (2008, p.111). Exploring the content of the ties between food, TB, diabetes and transnationalism threw forward a myriad of interdependent pathways. The connection between food and nutrition was recognised by the majority of the participants in this study, however, it appeared to be a difficult balancing act between the biological needs of a body (Hu 2011; van Lettow 2003), personal preferences, cultural expectations (Pollock 2009), shifts in environment (Candib 2007) and monetary constraints (Dunsford et al. 2011). The constant inner dialogue which existed for participants with regards to their own health was stressful. Part of this stress was a response to the anxiety of having to change food behaviours. Moreover, the stress of cultural events where food behaviours are on display to the wider community was both a contributor to stress and a factor of social isolation. In this way, stress was also seen to contribute syndemically with TB and diabetes and may also have led towards creating or exacerbating different types of stigma. Stigma appeared to operate at many levels of the syndemic. In particular I listened to stories of Cook Islanders receiving unwanted negative attention at community events, in the work place, at the clinic, and at home. These stories of negative attention in turn led participants to feel ‘different’ as well as retreat from social occasions.

Looking back, I believe that the literature had prepared me for the ‘othering’ experienced by TB patients (Wanyeki et al. 2007; Lawrence 2007 and Littleton and Park 2009), however, I was unprepared for the accounts of stigma expressed by those with diabetes. This raises two important issues. First I was unprepared because I had subscribed to ideas of diabetes being a matter of individual responsibility and a ‘lifestyle’ disease, a discourse which remains pervasive in both New Zealand and the Cook Islands. An important distinction is necessary here; my limitations in not recognising stigma amongst people with diabetes limited my research design, and as such, I did not fully explore this issue with health professionals. The second related point is that without considering the role of diabetes upon TB, I would never have encountered the internalised self-stigmatisation of some participants, nor the external stigma which was often directed from those very close to the participants (e.g. spouse). By considering the synergistic interactions of diseases and
harmful social conditions, new routes of enquiry were highlighted (Singer et al. 2011). The ideas of shame and embarrassment expressed by some of the participants came through most clearly during the analysis and needs further conceptualisation and more empirical analysis, particularly in the area of how health professionals approach this issue. Nevertheless statements from participants in this study below illustrate the deeply emotional impact of having diabetes.

**Figure 12:** How some participants expressed their emotional responses to diabetes

"I am a diabetes victim"  
“I will kick the bucket”  
“I will battle this [diabetes] myself”  
“It’s too late for the older people”  
“When I found out I had diabetes, that’s when my nightmare began”  
“I am ashamed”  
“I am going to die from this [diabetes]”

**Syndemic research as collaboration in motion**

Syndemic theory actively advocates for collaboration, which in this thesis speaks to engagement across disease categories, nation-centred responses to health services, and dialogue between the professionals who work in the areas of TB and diabetes. Furthermore, the main component of transnationalism in this thesis brings forward the need to bring social services, immigration and aid funded health programmes into the conversation regarding TB and diabetes. This research has highlighted an existing collaborative force which, with more capacity and capability, could work towards countering the syndemic. The Public Health Nurses (PHNs) in both countries operate as connectors right across the health concerns of Cook Islanders, including social services, housing, diagnosis and treatment. The nurses included in this study widely understood the personal experiences of people with TB and diabetes, including the types of stigma they faced. Syndemic research holds the promise of being able to communicate the synergistic factors which influence health outcomes, which, if interpreted as an additional resource to
biomedical explanations of disease, could influence the health practice. Out of this research I believe there are two development opportunities. The first opportunity is to prioritise the position of Public Health Nurses in both the Cook Islands and New Zealand health systems. More emphasis is needed on their ability to connect to services outside the bounds of disease treatment and into areas of social services including housing, health prevention and promotion. These nurses would benefit greatly from access to more social science and health promotion research. I believe that syndemic frameworks offer many opportunities in areas of professional development for health clinicians. The second opportunity is to reconfigure health promotion, health access, and health and development funding in light of synergistic disease and harmful social condition interactions. For example, housing affordability in New Zealand and housing conditions across the transnational social field need to be viewed as a health issue. Homes of Cook Islanders could also present a place where more health services, social services and health promotion activities take place for entire families. Cook Islanders in this study preferred the PHN approach of house visits and an opportunity exists for health professionals to affect food purchasing and cooking practices in these places as well. In addition, the links between stigma and diabetes signal the need for more emphasis to be placed on the mental health of those with diabetes. These opportunities would be more effectively designed and implemented via collaboration between both the New Zealand and Cook Islands government.

**Opportunities to “synerqise” funding**

While in the field I noticed how different frameworks pertaining to health and development were often juxtaposed with each other without making an evaluation of how they connected with each other. In the Cook Islands, the funding for a TB dedicated full time employee operates across other health issues. The funding is generous in consideration of low case numbers of TB therefore the resources are used in other areas where there are constraints. In this case, TB has been agglomerated with lung cancer and asthma. A connection was made between these conditions as pertaining to issues of the lungs, which although logical in one sense, disguises other potentially beneficial synergies. The syndemic framework in this thesis positively contributes to new ways of thinking regarding the governance of health funding by making a case to look widely at the connecting factors of health. I believe that understanding the TB, diabetes and transnationalism syndemic
highlights the relevance of aligning TB funds with those of diabetes and tobacco control and smoking cessation in the Cook Islands. Aside from the numerous benefits of educating the population about TB and diabetes and lowered rates of smoking, with more available resources, the issue of stigma and isolation of those with diabetes could also begin to be addressed.

The ability to synergise funding rests with sophisticated policy analysis, which is one area where the Cook Islands is constrained. However, the realisation that the “double burden” of TB and diabetes is a threat to the Pacific region and the Cook Islands has recently been responded to by the Cook Islands Ministry of Health in a manner which reflects a shift in operationalising health resources. For example, currently a research project is underway which seeks to investigate the risk of TB among diabetes patients via TB surveillance as a way to secure TB funding in the 2015 Global Fund round.

‘I went to the health’; Cook Islanders connected perspectives of ‘health’

In this thesis I have attempted to illustrate through pictures and narratives how Cook Islanders perceive health and their body in relation to TB and/or diabetes. Although I began conversations with ideas of health and disease more commonly associated in medical fields, different associations of health were conveyed by the participants. In this research I encountered the term ‘health’ in a range of ways which were culturally specific to Cook Islanders. For example, the term ‘health’ was a place to get your BSL tested and to get prescriptions, ‘health’ was also synonymous with healthy eating or simply a moment in time when no-one in the family was sick. To understand each of these more fully I looked to the research material and attempted to situate culturally constructed ideas of ‘health’ by situating them within the larger sets of relationships at play (Park et al. 2011). Overall, the narratives spoke to a broad but interdependent perception of health among the interview participants. Notions of health in the body, emotional health, environmental health and community health were expressed. The one notion I explored more fully, because of its relationship to health service access, was the idea that some physical spaces were “health”. For example, in Rarotonga, it is common place to hear “I went to the health”. In this respect, “health” is used as an abbreviation of ‘health clinic’ and symbolised that ‘health’ for
Cook Islanders had been mobilised from the absence of disease in a body to also include places of health.

The idea of places being healthy has a long history in the Cook Islands. For example, one of the remits of the Ministry of Health in the Cook Islands is to perform “Tutaka” which is a way for delegates to survey the ‘health’ of personal and commercial property and land. This usually occurs annually, although it may occur more frequently on some of the outer islands e.g. Aitu. During this time one of the focus points is to eradicate breeding and resting areas for bugs and pests including mosquitoes, flies, bed bugs, centipedes and cockroaches. Beyond environmental health checks the Tutaka also surveys the housing and health conditions of the elderly and babies, and the water supply and sanitation of households. These ‘health’ checks connect the ‘socially responsive physical environments’ (Park et al. 2011) surrounding peoples’ homes. The Tutaka also demonstrates that a synergistic view of health is already operating at some levels in the Cook Islands. For example, involved in the Tutaka (which includes the general population of all islands in the Cook Islands) are the Cook Islands Police, National Environment Service, Ministry of Infrastructure and Planning and Ministry of Finance and Economic Management. Overall, Cook Islanders have a connected view of ‘health’ which relates to their interactions with their own bodies (see chapter six), disease, social conditions, moving transnationally and the physical environment. The ethnographic methods used in this study, particularly multiple interviews with some of the participants, drew out personal constructions of health. How ‘health’ is perceived by Cook Islanders needs more attention because it has taken a minor role in this study. On the surface, this study has revealed that a broad view of health has been adopted which connects people to their surrounding environment and other people. As such, educating the communities and health work force on syndemics may be a good fit with existing concepts of health because a multidimensional perspective appears to already exist.

**Syndemics and story telling**

To engage with Cook Islanders’ experiences, practices and the meanings attached to the ideas of transnationalism and health, this research was conducted in multiple places across two national borders. My intuition was to conceptualise multiple and interacting contextual
layers determining the health of Cook Islanders, which when investigated via health and mobility stories, allowed me to visualise the syndemic operating in the format of a story. The story telling of the important events in the participants’ lives brought to the surface the key interactions at play (Marcus 1995). The complexities of the synergies, I argue, can be more fully understood via stories, which provide a platform for further discussion. It is important to note that the stories in this thesis have also been used as presentation pieces to a range of academic, medical and community audiences. In each setting, the stories effectively and evocatively conveyed the existence of the TB, diabetes and transnationalism syndemic. The case studies also facilitated collaborative discussions about the health of Cook Islanders in the Cook Islands and New Zealand. These discussions included presentations to the National Council of Women in the Cook Islands, the Auckland District Health Board, the Population Council of New Zealand, the Pacific History Association, The Health Research Council of New Zealand Pacific Fono, the Cook Islands Health Conference, the Ministry of Health in the Cook Islands, the Ministry of Health in New Zealand, Auckland University of Technology and the Centre for Development Studies at the University of Auckland. To put syndemic theory into action so that it can inform policy, I argue that story telling can both shift ways of thinking and make convincing arguments.

It is important to also state that the ability to draw out the stories and narratives in a way which looked specifically at syndemic connections was made possible by looking at the range of patterns across the transcriptions through the syndemic grid. The grid in chapter four organised the research material is a particular way which highlighted the connections between biologically and socially harmful conditions, which I felt I could attend to with stories and further narrative analysis. It performed a filtering function on the material I had collected and a way for the research to focus on particular themes. In hindsight, the conceptualisation of the grid part way through the field research phase could also have allowed me to follow key routes of enquiry to greater depth. The key connections which could need further empirical analysis are those which relate to gender and food behaviours.
Synergised methodologies

This research began from the discovery that more TB cases are recorded in New Zealand among Cook Islanders than in the Cook Islands. This is interesting because this pattern does not reflect what is conventionally attributed to TB case patterns globally, as higher case numbers are typically found in less developed countries (World Health Organisation 2006). This proxy started me down a path of enquiry which explored the particular issues at play for Cook Islanders (Abeyasekera 2005; Hesse-Biber 2010). The numbers also raised questions regarding the use of regional health targets and issues of regional aggregation (Banks and McGregor 2011). For example, did the evidence of low numbers of TB in the Cook Islands mean that health and development was reaching targets and translating to improved livelihoods? To answer this question I used TB as a way to identify a group of Cook Islanders to include in this research and an entry for discussion about the negative contributing forces on a person’s health (Farmer 2000; Freudenberg et al. 2006; Wallace and Wallace 1998). By considering this question my attention shifted away from the indicators of inequality and towards more nuanced understandings of disease and lifestyle factors including transnationalism. This departure from relying heavily on epidemiological and conventional health and development indicators aligned with my interest in the “important differences between even small numbers” (Banks and McGregor 2011). I discovered during the process of this study that whilst being definable in a biological sense TB also provides a way to investigate a breadth of social, economic and political factors, and a creative way to synergise different research methodologies.

According to Bastia et al:

the need for ever-widening range of actors to generate (and use) policy-relevant knowledge suggest not only a traditional process of research capacity building, but also that an understanding of policy-making processes and the capacity to form new relationships and linkages across institutional boundaries have to be built (2005, p.238).

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37 Between 2010 and 2011 there were seven new cases of TB in New Zealand. This represents 2.3% of the total new TB cases in New Zealand during this period. During the same period in the Cook Islands there was one reported case of TB (IESR and MoH CKI).
This thesis illustrates how different methods of data collection, analysis and creative presentations of results are possible with the use of a syndemic framework. Furthermore, I argue that syndemic frameworks shed light on areas of health and development funding which could be modified by recognising the connections.

**Making the syndemic connections visible via illustrations**

At different stages of analysis within this thesis, I have relied on illustrated and diagrammatic explanations of syndemics at play within the Cook Islands population. Aside from it being a personal preference to visualise complexity, these pictures also demonstrate my desire to work towards making the invisible more visible to the Cook Islands communities in both countries. I am referring to a range of invisibilities that I encountered along the route of this study. First, numeric representations of health appear insignificant when placed in large tables for comparisons. However, when these numbers are converted into visual displays of peoples’ experiences they become hard to ignore. I also wanted to create a health research project which was framed and delivered in way that could easily be communicated in a community setting. The illustrated stories in these settings have been well received. This is also part of my ethical belief that as researchers, we need to constantly find new ways to reach wider audiences and to also reciprocate to the communities who are situated within our research.

Perhaps the most important influence these illustrations have made as both an analytical process and output of the research is that they have allowed for a deeper understanding of critical theory, in particular, syndemics. Syndemic theory disrupted my own personal ideas of health and health service access, therefore constructions of health and health interventions were redefined. This was not an easy task, because I was simultaneously re-educating myself and others about the potential benefit of this theory. The illustrations and diagrams in this thesis serve the purpose of making syndemic frameworks more visible in the hope that this opens up new pathways for health and development in the Pacific region.

**Future research opportunities**

The most significant methodological constraint in this research was the amount of time dedicated to each place within the multi-sited ethnography. This study began with an
ambitious research design which was able to deliver on some aspects of the research but fell short on others. For example, transnationalism has been clearly conveyed to implicate the health of Cook Islanders. However, although I visited many places, my proximity to Auckland and length of time in Rarotonga has meant that my understanding of the Cook Islands transnational social field is strongest in, and between, these two places. This research unfortunately falls into the category of privileging the experiences of Cook Islanders who live in the largest city of New Zealand and the larger islands and atolls of the Cook Islands. Aside from needing to spend more time in Aitutaki and Porirua, future syndemic research studies must also incorporate the more isolated Cook Islands populations. In doing so, additional dimensions to the degree of health inequalities that exist across the transnational social field could be addressed.

The significance of gender, which has been flagged in this thesis, needs further in-depth research attention. The discussions with male participants in this study brought to the fore many issues relating to masculine identities of Cook Islands men, but also the relationship between health, stigma and gender. Similar experiences of stigma were expressed by the male participants across all the study locations, however, with more time and subsequent interviews I believe that this line of enquiry would produce specific insights into gender and health. This would broaden our understanding of how people with diabetes engage with different communities and how different communities engage with people with diabetes. Importantly, this research has demonstrated that syndemic frameworks can work well in areas of gender and development research. The next response to the needs of Cook Islanders’ health is situated within the consideration that not all experiences across the transnational field are homogenous. As Alexeyeff argues:

> While promoting notions of a ‘level playing field’ and gender neutrality, a growing body of work suggests that neoliberal approaches to international relations, trade and market economics are not only inherently gendered, but are also instrumental in promoting particular types of masculinity as well as femininity (2008, p.146).

Recognising the heterogeneity of Cook Islanders’ experiences of TB, diabetes and health service across the transnational social field is necessary. Via a syndemic framework, the issues of gender and health have been brought to light in this study. There is scope to further investigate how gender relates to delays in diagnosis and experiences of disease.
Alongside gendered differentiation, the syndemic framework in this research also suggests that responses to the health needs of Cook Islanders must also take into account place specific differences of health issues and respond to those accordingly.

There is also room to more widely explore the relationship between housing and the TB, diabetes and transnationalism syndemic. Because the time was limited, I was not able to investigate the position of housing within different environmental, economic and social realms. Overall, although the case studies speak to health and transnationalism operating across time and place this research would have been advanced by the opportunity to explore how different generations engage with the linkages between structural conditions, transnationalism and health over time. Although I was well positioned to do this with the strategy of conducting multiple interviews with some participants, it would have been beneficial to include the voices of other people in the family setting.

The other perceived weakness in this thesis is the inability to analyse the extent to which the nation centred responses to health of Cook Islanders are conceived and implemented by health and policy professionals. This study evolved into a largely ethnographic, grassroots project, and less attention was placed upon the historical and political designs of the health systems. The health systems were traced in a way which allowed for greater understanding of the paths that Cook Islanders navigate. This thesis raises many issues of nation centred responses to health which need further investigation. Central to this investigation are the implications that colonialism, citizenship, nationhood and sovereignty place upon health service access for Cook Islanders.

A road map to syndemic research

Within this reflexive juncture of the thesis I have one final conceptual tool to propose. Bastia et al. make a call for “an environment that is conducive to social development research and experimentation with new methodological ideas, as well as to the uptake of findings that are generated” (2005, p.237). One of the ways that I have attempted to reach audiences with the findings in this thesis is by being explicit and transparent in my syndemic methods. Upon reflection on my methods, I began to conceptualise the path the research had taken as it weaved in and out of different contexts and across health and social condition categorical boundaries. Thinking about this path transpired into a
“syndemic research road map”. This conceptualisation allowed me to reengage with the ideas presented in chapter seven. The road map in Figure 13 illustrates a simplistic way to mind map the coordination of different aspects of using a syndemic framework.

Although this road map is linear in direction from beginning to end, it allows me to illustrate how I engaged and interrogated the different contextual, theoretical and empirical layers of the research. There is circular causality to syndemic research, where each understanding leads into the next level of interconnected complexity. The final layer, which is addressed below, is whether or not nation centred responses to Cook Islanders’ health are sustainable.
TB and diabetes are both windows into global social and health inequality.

For Cook Islanders, both of these health issues occur within a transnational social field between the Cook Islands and New Zealand.

Literature review of syndemics reveals the possible existence of a TB and diabetes syndemic within the Cook Islands population.

Channels and mechanisms of this syndemic can be explored through interviews and observation with participants in Auckland, Porirua, Aitutaki and Rarotonga.

Narrative analysis and further review of the literature reveals a set of high level findings that indicate the existence of the TB and diabetes syndemic for the Cook Islands population.

The high level findings reveal that a key channel and mechanism for Cook Islanders is transnationalism.

The proposed notion of a TB, diabetes and transnationalism syndemic is explored through case studies. When illustrated these case studies reveal the complexity of the biological, social, cultural, political and economic forces at play. Key events in the case studies provide evidence of a TB, diabetes and transnationalism syndemic.

Key interacting connections within the TB, diabetes and transnationalism syndemic are distilled and explored through narrative analysis.

Interrogation of nation centred responses to TB and diabetes and how this raises the risk of the TB, diabetes and transnationalism syndemic for Cook Islanders. New opportunities for health research are proposed through the application of a syndemic framework.
Health, citizenship, and responsibility

The stories of Cook Islanders in this thesis are presented as socially constructed and situated in political-economic and cultural contexts (Lawson 2000). These contexts are seen to influence health altering mobility. Anecdotally, I would argue that Cook Islanders are aware of this scenario; however, without contemporary frameworks and research methodologies, isolating the probable causes and solutions is difficult. The transnational orientation of this study in combination with a syndemic framework attempts to address a lack of discussion around health, citizenship and responsibility in this region. Because Cook Islanders weave in and out of different health promoting or demoting environments and come into contact with disparate health services across multiple countries, responsibility for health is spread across two nations. Traditionally, we conceptualise the country of residence as responding to the health needs of its citizens, but how do we deal with this issue in a transnational setting with a highly mobile population? Questions such as these are relevant not only for the Cook Islands population but other highly mobile groups who transcend national boundaries. As Spoonley et al. argue:

The creation of new transnational linkages and social/cultural spaces has diminished the significance of borders, and altered the shape of those (national) identities that are contained within boundaries, along with the regulatory frameworks and narratives that underpin such constructions (2003, p41).

To conclude this thesis I address the issue of responsibility within the framework of syndemic theory. How is citizenship, the nation and health conceived under transnationalism? I would argue that Cook Islanders who are citizens of New Zealand and the Cook Islands provide a unique future opportunity to explore a nation bounded response to health services. This adds a further dimension to the scrutiny that New Zealand and other colonial powers are receiving with regards to contemporary relationships with past colonies (Banks et al. 2012; Banks and McGregor 2011; Teiawa 2012). Before proceeding it is worth mentioning that some examples of transnational or cross border responses to the health of Cook Islanders currently exist. Those specific to this research include relationships between the Counties Manukau District Health Board and the Cook Islands Ministry of Health, flows of equipment, specialists and knowledge between the two countries and official referrals between the Cook Islands and New Zealand. Moreover, the way in which transnationalism has altered expectations of health services has delivered
positive outcomes for some Cook Islanders. However, although these exist within the transnational social field, they still operate in a way which suggests that Cook Islanders (in both countries), despite New Zealand citizenship, occupy a different space in health and social services to New Zealanders. This has been illuminated by the accounts of Cook Islanders who have for various reasons experienced exclusion from health and/or social services in either New Zealand or the Cook Islands. Citizenship, identity and health service access for Cook Islanders’ and other Pacific peoples presents new avenues for research.

Syndemic theory urges researchers to look beyond singular or dualistic constructions of health, and as such, I believe that the theory signals the need for Cook Islanders health to be considered beyond being ‘at home’ or in ‘New Zealand’ and instead existing across and within both nations. Park et al. consider a similar situation to be occurring for Tuvaluan’s across transnational space:

New Zealand has clearly recognised certain needs of Tuvaluans ‘over there’ in Tuvalu, and has responded to them through aid programmes. It appears to have built a positive reputation in Tuvalu as an aid and assistance donor. However, this good neighbourliness to Tuvaluans and its residents is not matched by a similar focus on the needs of those Tuvaluans living transnational lives (2011, p.23).

In the quote above it is argued that New Zealand responds differently to the same population depending upon residency status and indeed proximity to New Zealand society. New Zealand’s different responses to Cook Islanders who live in the Cook Islands or New Zealand complicates health service access, and is another level of harmful “additive interplay” (Stall et al. 2003) within the interaction of biological and socio-political conditions in the syndemic. My interpretation of the question “who is responsible for Cook Islanders health?” within syndemic theory instead becomes more action orientated. Alternatively, the question becomes “how can we more effectively respond to the health needs of Cook Islanders?” This shift does not demote the question of responsibility in terms of health and citizenship, but instead advocates syndemic theory as useful for not only conceptualising the problem but also providing possible counter syndemic solutions. Syndemic theory’s

38 People of Tuvalu are not citizens of New Zealand.
strength lies in its ability to isolate key areas where changes could be made to address the unequal burden of disease.

**Developing syndemic responses**

One of the most important ways that we can respond to the health needs of Cook Islanders is to rethink and reformulate health policies so that they are “no longer automatically equated with the boundaries of a single nation state” (Levitt and Glick-Schiller 2004, p.1002). Transnationalism has in this thesis been demonstrated to exert a negative influence on Cook Islanders health, however, positive aspects of globalisation may actually hold some of the solutions to Cook Islanders' navigating multiple health systems. According to Vertovec “much needs to be done to realise the full civic potential of technology and communications” (1999, p.454). The influence that technology has had on transnationalism and identity in the Pacific is already a topic of discussion (Macpherson and Macpherson 2009; Spoonley et al. 2003). There are also existing positive examples of how Pacific peoples strategically use technology for identity shaping, political mobilisation and resistance (Spoonerley et al. 2003). I argue that there is room to expand this discussion into areas of technology, transnationalism, development and health in the Pacific. Internet access is now available in all of the Cook Islands, and health reporting systems could be streamlined and integrated across the Cook Islands and New Zealand. This would allow Cook Islanders' health histories and medical records to be available to clinicians across the transnational social field. Timely diagnosis and the effective treatment and management of both TB and diabetes correspond to decreased associated health conditions and a lowered risk of the TB and diabetes commodity. This is however threatened by delays in diagnosis and interrupted and ad hoc access to medical services. This is one example of how global, macro level processes could interact with the lived transnational experiences of Cook Islanders to produce positive health outcomes. Moreover, with rising recognition of the interaction between disease and social conditions these information systems could be reconfigured to include a wider range of interacting variables along with medical symptoms and diagnosis. Advances in technology which expand across nations could simultaneously demonstrate and illustrate how the Cook Islands population is ‘expanding’ across nations (Hau’ofa 1994).
The final suggested response in light of the application of a syndemic framework, is to place more attention upon the relationships between nutrition, international trade agreements and rising food prices and diabetes. This will require investigation across many places, each with their own sets of environmental and economic constraints to food access in order to appropriately understand the relationship between Cook Islanders’ food behaviours and the rising rates of diabetes. More emphasis is needed on the synergies between the cultural, social, economic and political dimensions of food and Cook Islanders to more fully understand the current situation of diabetes and the risks for the future. The absence of this research to date reveals a troublesome situation whereby health research in the Pacific is focused upon the agendas of international donor countries and agencies, and complex and ever changing trade agreements. Syndemic research, with its holistic approach, provides a contemporary path to reinvigorate health research that is conducted by and situated with the populations who are experiencing unequal burdens of disease. Health, identity and citizenship are relationships that need exploring in greater depth, not just with Cook Islanders but amongst other Pacific populations, each with their own sets of historical, political and migratory links to New Zealand. As Mila-Schaaf argues:

Identity is determined by genealogical connections as well as inherited and created relationships. This is how people understand their place within the world; as positioned within a relational force field of interdependence (2009, p.135).

This thesis suggests that the TB, diabetes and transnationalism syndemic will be sustained unless interventions which deal with specific interactions are designed and delivered in a way which responds to Cook Islanders transnational livelihoods. Within this chapter a few possible interventions have been suggested as ways to counter the syndemic. These interventions have centred upon how the New Zealand and Cook Islands governments can better respond to Cook Islanders. However, interventions and responses which counter this syndemic also need to be seeded at the population, community and individual level. In this thesis, Cook Islanders have recounted numerous ways in which they have strategically navigated complex health and social systems which transcend national borders. In this population there already exists an ability to map needs and desires across a complex transnational field containing multiple social and political structures. I believe that for Cook Islanders to counter this syndemic and to move towards more sustainable positive health outcomes for the majority, they must be made more aware of not just biological health,
“but of the health effects of colonial and post-colonial social, political, and economic relations” (Park et al. 2011, p.7). I believe that syndemic frameworks can deliver such knowledge and could help redesign culturally specific interconnected health systems for Cook Islanders.
## APPENDIX ONE: Key participant profiles

<table>
<thead>
<tr>
<th>Name</th>
<th>Case study</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>John Lindsay</td>
<td>Case study 1</td>
<td>A very mobile Rarotongan currently living in Auckland. He has haemodialysis three times a week. His kidneys failed as a result of diabetes. He was diagnosed with TB in 2011.</td>
</tr>
<tr>
<td>Ta’i</td>
<td>Case study 2</td>
<td>Rarotongan male living in Rarotonga who was diagnosed with diabetes as a result of an infected finger injury from gardening.</td>
</tr>
<tr>
<td>Papa Saul</td>
<td>Case study 3</td>
<td>Elderly Aitutakian living in Aitutaki who has diabetes. He was transferred to Rarotonga for TBD and diagnosed and treated for TBD in Rarotonga in 2007. His experiences in hospital in Rarotonga were referred to as being in a “jail”.</td>
</tr>
<tr>
<td>Tu</td>
<td>Case study 4</td>
<td>Rarotongan father living in Porirua. His brother had TBD and later died from complications from his diabetes. Tu uses a peritoneal dialysis machine at home. His kidneys failed as a result of his diabetes.</td>
</tr>
<tr>
<td>Rangi</td>
<td>Case study 5</td>
<td>Rarotongan father living in Auckland with his wife and six children. His mother was on haemodialysis because of kidney failure associated with diabetes. Rangi’s mother died of TB and his family have had a complicated history of the disease since this time.</td>
</tr>
<tr>
<td>Anabelle</td>
<td></td>
<td>Elderly Maukean woman living in Auckland who has diabetes and was diagnosed with TB in 2010.</td>
</tr>
<tr>
<td>Tupou</td>
<td></td>
<td>Aitutakian father living in Rarotonga who was diagnosed with diabetes as a result of the injury on his foot.</td>
</tr>
<tr>
<td>Solomon</td>
<td></td>
<td>Rarotongan father in his 50s who had TBD as a high school student in Wellington. Lives in Porirua and has diabetes.</td>
</tr>
<tr>
<td>Kiri</td>
<td></td>
<td>Rarotongan woman living in Porirua who works as a social worker. She has many experiences working with Cook Islanders who have either TB or diabetes.</td>
</tr>
<tr>
<td>Sam</td>
<td></td>
<td>Young male who arrived in New Zealand as a feeding child from Rarotonga when he was a young child. He was diagnosed with TB in 2011 after several months of misdiagnosis.</td>
</tr>
</tbody>
</table>
"Health and Mobility: Cook Islanders route to health services" is a PhD research project from the Centre of Development Studies at the University of Auckland.

Health services available to Cook Islanders are located in both the Cook Islands and New Zealand. This research will look at how Cook Islanders access health services within the Free Association arrangement that accords Cook Islanders New Zealand citizenship. While I am interested in health broadly, I am focusing on tuberculosis because it is a disease that places people in prolonged contact with health services.

This research is located in Rarotonga, the outer islands, and New Zealand because experiences of health services are strongly influenced by their availability. The different health services available to Cook Islanders depending upon where they live signals the need for research on the comparative experiences of health service access in a range of places. With this in mind, the primary research will begin in Rarotonga and Auckland and move from there. The research is expected to take three years.

The research includes Cook Islanders who have had experiences of tuberculosis (as a patient, family member, support person), as well as Cook Islanders and non-Cook Islanders who work with TB patients. Policy workers and health stakeholders in the Cook Islands and New Zealand health systems will also be interviewed. Approximately 30 participants will take part.

It is anticipated that this research will shed light on how the political relationship between the Cook Islands and New Zealand is played out in the daily lives of those living with disease and assist our understanding of the experiences of Cook Islanders living with TB and other diseases.

This study has received ethical approval from the Multi-region Ethics Committee of New Zealand which reviews National and Multi-regional studies. MEC 08/07 076. It also has the approval of the Government of the Cook Islands Research Committee.

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APPENDIX THREE: “Transnational Health in the Pacific through the Lens of TB” Participant Information sheet

Principal Investigator:
Associate Professor Judith Littleton
Department of Anthropology
University of Auckland,
Private Bag 92019
Auckland

7 August 2008
Phone: 3737599 x88574

Name of Study: Transnationalism in Pacific health through the lens of tuberculosis

Introduction
You are invited to take part in a study of the relationship between Pacific people’s links with New Zealand and the Pacific and their health - past and present. In particular we are interested in tuberculosis (TB) and related conditions. Your participation is entirely voluntary. If you choose not to take part you will receive the usual medical treatment. We will contact you in approximately one week to see if you are willing to take part in this research.

About The Study
The aim of the study is to find out about the successful treatment and prevention of TB and related conditions in New Zealand, the Cook Islands and Tuvalu. We are seeking to identify effective interventions and the barriers to them and to produce culturally specific information about TB and related conditions.

We are interviewing people of Cook Island or Tuvaluan descent who have had TB in the past or at present, people who have had TB patients in their families or among their friends, health professionals who work in the area of migration and health, and members of the community. TB patients and their families will be identified by health care workers as well as through community networks. Recruitment of community members will be through community networks.

Approximately 100 participants will take part.

The study will take place in various places in the Auckland, Whangarei and Tokoroa areas and possibly other areas in New Zealand as well as in the Cook Islands and Tuvalu.

The time span for this study is four years.

The research has been funded by the Health Research Council of New Zealand and the University of Auckland.

The study will consist of interviews of approximately one hour. People who have or have had TB will be asked for up to three interviews; other participants for one. The interviews will be
audio-taped. With the participant’s permission the audio-tape will be deposited in an oral history archive where it can be accessed by genuine researchers approved by the Archive management, who will agree to preserve interviewees’ anonymity. All other tapes will be destroyed on the conclusion of the study. When tapes are transcribed, transcripts will be archived under the same conditions, with the participants’ permission. Otherwise the transcripts will be destroyed after ten years.

**Benefits, Risks and Safety**
The study aims to benefit Pacific peoples with TB and other health issues and their communities in New Zealand as well as in the Cook Islands and Tuvalu by understanding what creates successful prevention, control and treatment.

The study poses no risk and the only inconvenience is the time taken for interview.

Participants will be offered a small gift, e.g., fruit.

**Participation**
If you do agree to take part in this research you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your health care.

**General**
Your doctor or nurse will be told you are in the study, only if you give us permission to access your medical records.

If you want more information about this study you can access the website via the anthropology department [http://www.arts.auckland.ac.nz](http://www.arts.auckland.ac.nz) or contact one of the researchers.

If you need an interpreter, one can be provided.

You may have a friend or family member to help you understand the risks and/or benefits of this study and any other explanation you may require.

During the interview you do not have to answer all the questions, and you may stop the interview at any time.

If you are a health professional taking part in this study, if you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act (NZ).

Telephone 0800 555 050, Free fax 0800 2787 7678, email advocacy@hdc.org.nz (New Zealand wide). [An arrangement will be made in Tuvalu and the Cook Islands for an external person (or persons) with community standing to act as advisors in a role comparable to the NZ H&DC. Contact details will then be added to this information sheet.]

If you incur travel costs to interviews, we will refund them.

**Confidentiality**
No material which could personally identify you will be used in any reports on this study. During the study the data will be kept in locked University of Auckland facilities.
Results
This study consists of several different components that will be completed between 2009-2011. Results of the study can be accessed on the website noted above. For those participants who wish it, copies of summary reports will be available. The study will also be published in academic and health journals. At times during the study period, oral presentations on the study will be given to community groups, health professionals and others.

Statement of Approval

This study has received ethical approval from the Multi-region Ethics Committee of New Zealand which reviews National and Multi regional studies. MEC 08/07 076

Please feel free to contact the researcher if you have any questions about this study.
Consent Form (In-depth health interviews)

Name of Study: Transnationalism in Pacific health through the lens of tuberculosis

<table>
<thead>
<tr>
<th>English</th>
<th>I wish to have an interpreter.</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cook</td>
<td>Kai i mungaro ai tetai langata u ri reo.</td>
<td>Ae</td>
<td>Kare</td>
</tr>
<tr>
<td>Island</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuvaluan</td>
<td>Au e manako se tino mo teseasona mo te fuliga ki te 'gana faka nanina.</td>
<td>E</td>
<td>Ilai</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I have read and I understand the information sheet dated ______________ for volunteers taking part in the study designed to investigate health knowledges and practices as they relate to tuberculosis and related conditions.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.
I consent to my interview being audio-taped
YES/NO

I consent to a copy of the audiotape being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet
YES/NO

I consent to my transcript being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet
YES/NO

I wish to receive a copy of my transcript
YES/NO

I wish to receive a copy of the summary report
YES/NO

I consent to my medical records that relate to tuberculosis being sought
YES/NO

I______________________________________ (full name) hereby consent to take part in this study.

Date
Signature

Full names of Researchers:
Associate-Professor Judith Littleton phone 3737599 x88574
Associate-Professor Julie Park, phone 3737599 x88589
Dr Yvonne Underhill-Sam, phone 3737599 x82311
Dr Ward Friesen, phone 3737599 x88612
Dr Jennifer Hard, phone 3737599 x87645
Associate Professor Robin Keams phone 3737599 x88442
Associate-Professor Linda Blythe phone 3737599 x87319
Dr Phyllis Hinda, phone 3737599 x88111
Dr Pat Nanzwell, phone 3737599 x82113
PhD Candidate Evelyn Marsters 0210790488
Project explained by

Project role
Signature
Consent Form (community members and health professionals)

Name of Study: Transnationalism in Pacific Health through the lens of tuberculosis

REQUEST FOR INTERPRETER
(to be included on all consent forms)

<table>
<thead>
<tr>
<th>Language</th>
<th>Request in Language</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>I wish to have an interpreter.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Cook Island</td>
<td>Ka irangaro anu i teti tangata uri reo.</td>
<td>Ace</td>
<td>Kere</td>
</tr>
<tr>
<td>Tuvalu</td>
<td>An e manako se tino mo fiscasoani mo te filiga ki te 'gana faka inatou.</td>
<td>E</td>
<td>Ilai</td>
</tr>
</tbody>
</table>

I have read and I understand the information sheet dated August 26 2008 for volunteers taking part in the study designed to investigate health knowledges and practices as they relate to migration and tuberculosis.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

Version 2/ 10/06/2013
I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.

I consent to my interview being audio-taped

YES/NO

I consent to a copy of the audiotape being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet

YES/NO

I consent to my transcript being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet

YES/NO

I wish to receive a copy of my transcript

YES/NO

I wish to receive a copy of the summary report

YES/NO

I __________________________ (full name) hereby consent to take part in this study

Date

Signature

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Dr Ward Friesen, phone 3737599 x88612
Dr Jennifer Hand, phone 3737599 x87645
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Dr Phyllis Herda, phone 3737599 x88111
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Evelyn Marsters phone 0210790488

Version 2/ 10/06/2013
REFERENCE LIST


Institute of Environmental Science and Research (2012). *New Zealand Tuberculosis case number data*. Wellington: Institute of Environmental Science and Research.


Lawrence, J. (2007). Placing the Lived Experience(s) of TB in a Refugee Community in Auckland, New Zealand (Doctor of Philosophy). University of Auckland, Auckland.


