

The Place of Tuberculosis

**The lived experience of Pacific peoples
in Auckland and Samoa**

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ABSTRACT

There has been a worldwide resurgence in tuberculosis since the 1990s. This is a major public health in terms of burden of disease and illness. The fact that TB is a preventable disease poses questions as to why rates of the disease are increasing. New Zealand's resurgence in TB involves rates and incidences of that vary across ethnic groups. Currently, Pacific peoples have four times the rate of TB compared to the rest of New Zealand and have the second highest rate of the four "ethnic groups", Pakeha, Maori, Pacific peoples and 'other'. Further the incidence of TB is concentrated in Auckland, which is home for 67% of all Pacific peoples in New Zealand.

This thesis examines the lived experience of TB of Pacific peoples in Auckland and Samoa within a political ecology framework, with the purpose of investigating some of the social determinants of TB. This investigation explores the health-seeking behaviour of Pacific TB patients and how cultural identity, health beliefs and social networks impacts on this experience. In conjunction with participant, thirteen interviews were conducted with TB patients in Auckland and Samoa and two focus groups were carried out in Auckland to examine the health beliefs and perceptions of Pacific peoples who had no personal experience of TB.

The results of this thesis suggest that for Pacific people's experience of TB is informed by an amalgamation of Pacific health perspectives and western biomedical perceptions. These perceptions are negotiated in a context of changing health and immigration realities. The thesis concludes that TB is still a stigmatised disease for those with a health culture of TB and that Pacific people's still use traditional medicine extensively. Further, migration is a social stressor that can activate TB. More research needs to be done in relation to the delay of seeking western medical attention by Pacific peoples. Finally, more information about the recent developments in TB needs to be more accessible to the general public to combat with the stigma of the disease and assist with treatment compliance.

Keywords: Pacific peoples, tuberculosis, identity, health perceptions and social networks.

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Chapter 1

Introduction

“One in three people are infected with TB worldwide.”
WHO, 2005

1.1 TB, a global phenomenon

In most people’s minds, tuberculosis (TB) is a disease of the past. However, the reality is that today, as quoted above the World Health Organisation estimates that TB infection affects one in three people worldwide resulting in three million deaths every year (World Health Organisation, 2005). This is an alarming figure especially in terms of public health due to the burden of illness and death. Like many other infectious diseases, TB is a preventable, treatable and in most cases curable disease. In essence, mortality from TB should almost be non-existent. During the 1970s it was thought that TB would inevitably be eliminated, unfortunately since the 1980s there has been resurgence in both developing and western nations. The geography of TB has therefore caused global concern as cities in both Western and Developed countries across the globe have been affected with outbreaks (Gandy and Zumla, 2002).

In response to this global resurgence the WHO in 1993 called TB a global emergency. This pronouncement acted as a catalyst for many recent studies into TB in order to understand why rates of TB are, in fact, growing instead of declining. Biomedical literature and perspectives provide the biological factors and explanations of the disease, but this is only part of the story. TB is infectious and, as such, human agency is an important factor in understanding the disease. Therefore, what is also needed is a disease ecology approach where, along with biomedical science, the social determinants of TB are acknowledged.

The disease ecology argument is that the distribution of, especially infectious disease,

cannot be understood without knowing about its relationship to local and regional ecologies (Gatrell, 2002). Disease ecology can assist greatly in understanding disease emergence and resurgence. A key principle is that population, society and both the physical and biological environments are in dynamic equilibrium (Mayer, 2000). Any stresses or changes associated with these factors results in an imbalance which enables either the emergence or resurgence of disease. However one other approach which is more robust in analysing the social determinants of TB is political ecology. A political ecology approach combines both disease ecology with elements from political economy to demonstrate that disease has both human induced components and natural components (Mayer, 2000). Fundamentally, political ecology contends that unintended aspects of human action contribute to the causality of disease.

1.1.1 TB in New Zealand

New Zealand, similarly to other developed nations, is now experiencing resurgence in TB since its plateau in the 1980s (Crump et al, 2001). The national rate of TB disease was 11 per 100,000 in 2003, with an average annual notification rate of 21 per 100,000 for Auckland (Thornley, 2005). The epidemiology of TB for Auckland is different to that of the rest of New Zealand because of the composition of its population. Auckland has a larger proportion of Pacific peoples (13.7%) and Asian people (18.7%) compared with the whole of New Zealand (at 6.5% and 6.6% respectively) (Statistics New Zealand, 2004). TB has long been associated with migrants in western nations and this association has been supported by statistical data showing that migrants are disproportionately overrepresented in terms of TB cases (King, 2003). Currently, Pacific peoples have four times the rate of TB than the total New Zealand population and constitute the second highest rate in the country (Ministry of Health, 2004). However, as statistics do not provide a comprehensive picture of TB and migrants. Rather, a comprehensive case study and research is needed to examine the relationship between migrants and TB.

1.2 Purpose of this thesis

As part of a larger project on the political ecology of tuberculosis in Auckland, I examine in this thesis the relationship between Pacific peoples and TB in Auckland and Samoa. My approach is geographical. In order to attain a better understanding of

the resurgence of TB in Pacific communities in Auckland through the lived experiences of Pacific TB patients in terms of their experience of place and migration is considered. This geographical approach also offers perspectives on the determinants of disease given that human action and behaviour are emphasised in conjunction with biomedical concepts. Such an approach emphasises the links between place, culture and identity (Gesler and Kearns, 2002). I investigate the health-seeking behaviour of Pacific TB patients and how cultural identity and health beliefs impact on this behaviour, how social networks are utilised by the TB patients and the social stressors that can activate TB for Pacific peoples. Finally, this thesis identifies some policy and practice implications to improve the health status of Pacific Peoples.

1.3 Epidemiology of tuberculosis

Tuberculosis is caused by the germ, *mycobacterium tuberculosis*¹, an infectious external organism (Curtis, 2004). There are three types of mycobacterium tuberculosis but they all cause the same illness. TB is transmitted through the air. A person becomes exposed to TB when the bacteria are inhaled into the lungs. TB is spread when an infected person is singing, talking, sneezing or coughing in a confined space over a long period of time (Klov Dahl et al. 2001). For this reason, there is a high transmission rate among living in close proximity to each other. Only a small amount of TB bacilli needs to be inhaled in order for a person to become infected (Gandy and Zumla, 2002). After infection the bacteria can progress into either tuberculosis disease (TBD) or into latent tuberculosis infection (TBI). The immune system “walls off” the TB bacilli so that it may lie dormant, until such time as it becomes activated and progresses into the disease (World Health Organisation, 2005). This distinction is important as people can go their whole lifetime living with TB infection but never having the actual disease.

Left untreated TB disease can be fatal. TB is most common among those who are immunosuppressed such as the elderly, infants and people with HIV. Disease, poor nutrition and psychological stress can all suppress our immune system and allow the progression of TB infection to TB disease (McDade, 2005). The disease may be pulmonary where the disease is in the lungs, extra pulmonary where the disease has

¹ It can also be caused by the bovine form *Mycobacterium bovis*

moved out of the lungs or a combination of both. Only five to ten per cent of the people who are infected with TB bacilli experience the onset of TBD (World Health Organisation, 2005.). The main symptoms of TB are increased tiredness, night sweats, weight loss and a cough of more than three weeks (Auckland Regional Public Health Service, 2005).

One worrisome feature of the resurgence of TB is the growing prevalence of drug-resistant strains or multi drug resistance TB (MDR-TB). MDR-TB poses a major problem to public health as treatment is both complex and expensive. Since the development of anti-TB drugs 50 years ago, strains of TB have now emerged that are resistant to all major anti-TB drugs (World Health Organisation, 2005). The emergence of MDR-TB has been the result of inconsistent or partial treatment where patients, for whatever reasons, do not take the full course of antibiotics, doctors and health workers have prescribed the wrong regimen of treatment, or there has been an unreliability of drug supply (World Health Organisation, 2005). MDR-TB rates vary across the globe with some countries; especially in the Western European bloc having significant rates (Curtis, 2004). Fortunately this is not a major problem for New Zealand (Stehr-Green, 1992; Cameron and Harrison, 1997).

Patients with HIV are more susceptible to developing MDR-TB. HIV sufferers who have TBI have over a 50% chance of TBI progressing into TBD compared to 10% for others. TB accounts for about 13% of AIDS deaths and is the leading cause of death among HIV positive patients across the globe (World Health Organisation, 2005). It is estimated that 20% of TB cases in Africa are HIV related (Curtis, 2004). Co-infection complicates treatment for TB and therefore leads to increased transmission because there are more source cases (Curtis, 2004). In New Zealand there are low levels of TB-HIV co-infection (Carr et al, 2001).

There is a vaccination for TB which is the Bacille Calmette Guerin (BCG) vaccination. From 1950 to 1980 the vaccination was given to all school-aged children. Now only newborn babies deemed at risk are given the vaccination where protection can last up to 20 years (Ministry of Health, 2003). According to the Ministry of Health, those deemed at risk are defined as those who;

- Will be living in a household with someone who has recently arrived from a high incidence country
- Will be living with someone who has or had tuberculosis
- Will be living in a high incidence area (incidence is greater than 5 per 100 000 population)
- Have one or both parents who identify themselves as Pacific peoples
- During their first five years will be living in a high incidence country for 3 months or longer

However, the BCG vaccination is not as efficient for older children and adults.

1.3.1 Treatment of TB

Case finding is the most important factor for TB surveillance. Detection and cure are the foundation of TB control. However, treatment is based on the premise that active TB is found (Klovdahl et al, 2001). Therefore, contact tracing becomes essential in order to control the spread of TB. Once TB is detected a treatment regimen begins whereby patients are given a course of anti-TB medicines. Once a course has started the patient will either administer their medication on their own which is known as self-administered treatment (SAT), or they will be referred to directly observed therapy (DOT). This is the procedure whereby a supervisor trained in the administration of DOT is physically present to witness the patient swallowing the medication for all doses during the course of treatment (Ministry of Health, 2005). At the end of 2003, 182 countries were implementing DOT so that 77% of the global population are living where the DOT strategy has taken place (World Health Organisation, 2005).

New Zealand does not implement Universal DOT, where all TB patients use DOT. This is because of New Zealand's low rates of drug resistance and reactivation rate² deem it unnecessary (Carr et al, 2001). The Ministry of Health (2002) in its *Guidelines for Tuberculosis Control in New Zealand 2003* recommends DOT for:

- all cases resistant to rifampicin
- all multidrug-resistant cases (resistant to isoniazid and rifampicin)

² Where a person has another relapse of TB after initially being cured.

- all relapses/reactivations
- all patients who clearly demonstrate an inability or unwillingness to self medicate
- all patients who have been placed under closer supervision and who then need continued help with treatment.
- people should also be considered for DOT when there is extensive disease and/or a high degree of infectiousness, weak or absent social support and a complex treatment regimen.

Although the drugs for TB treatment are inexpensive the real difficulty in the treatment of TB is the length of time for treatment. The minimum period of treatment for TB is six months and on DOT the doses have to be administered twice weekly (Thornley, 2005). In New Zealand the Regional Public Health Services are responsible for ensuring that every patient on DOT is appointed a public health nurse.

One noteworthy aspect of TB treatment and access to health services in general, is that frequently those people who need assistance services the most have limited access to health services and resources. Making treatment and preventative resources more accessible to marginalised populations is therefore, important for public health services in developing rural areas as well as western urban centres (Curtis, 2004).

The treatment of TB places a large burden on public health services. The cost involved for TB drugs for patients without complications are minimal. However the costs for MDR-TB and co infection are substantial. Administering DOT and contact tracing also require substantial investment in terms of finance and time.

1.4 Geography of health

The present study of TB among Pacific peoples in Auckland and Samoa is situated within the geography of health. Health geography is primarily concerned with how we can understand variations in health for populations in different parts of the world (Curtis, 2004; Gatrell, 2002). From a geographical perspective it is important to understand a person's sense of place and identity as this impacts on their notions and ideas of health and health seeking behaviour. 'Health' is such a socially constructed

term in that it has different meanings for different people. These meanings are deeply interwoven and attached to a person's individual and cultural identity (Gesler and Kearns, 2002). Gatrell (2002), for instance, argues that an understanding of identity is imperative as identity impacts on our ideas of health and the body. The construction of a person's identity is complex and is embedded within their socialisation experiences. Identity shapes and influences explanatory frameworks and health paradigms.

Health is a cultural concern and therefore requires inquiry into cultural domains of geography such as 'place'. An analysis of place allows an examination into how places may be good or bad for health (Gatrell, 2002). This inquiry into place needs to consider that for individuals there are variations in the significance of different places with changes in location, experience of place and identity. Using Eyle's (1985) idea of a person's place-in-the-world or sense of place, we can further examine how place impacts on people's identity and conversely how people's identity impacts on place (cited in Kearns, 1993). Place changes in significance with change in location, sense of place and identity. With the recursive notion of place or location and identity, place becomes an important spatial context for health.

Thus, for Pacific peoples living in Auckland, notions and perceptions of health are not necessarily the same as Pakeha, the dominant ethnic group in New Zealand. Pacific peoples have their own health perspectives and frameworks which have been shaped by cultural attitudes, beliefs, social mores and values. It is important, however, to note that there is no one generic Pacific health framework as such. As migrants in New Zealand, Pacific people's experience of health is informed by a combination of traditional perspectives, western science and changing immigration realities.

1.5 Pacific peoples

It is important to establish that the term Pacific is not meant to homogenise the island nations but rather to describe a collective of societies with distinct commonalities. Although the Pacific encompasses a vast area comprising many island nations not all these nationalities are considered in this thesis. Rather, this research focuses on the south-west pacific nations of Samoa, Tonga, Tuvalu, Cook Islands, Niue and Tokelau

as they are the major Pacific groups that reside in Auckland, as outlined in the table below:

Table 1.1: New Zealand Census counts by Island population estimate³.

Ethnicity	New Zealand Census Count	Pacific Island Population Estimate
Samoan	115,017	170,900
Cook Island Maori	52,569	19,300
Tongan	40,716	99,400
Niuean	20,148	1,900
Tokelauan	6,204	1,500
Tuvalun	1,965	10,000

Source: Statistics New Zealand, 2003

I provide a more detailed demographic overview of Pacific people's in Chapter 2. What is important to note here is that research on Pacific peoples in New Zealand has been so prolific that Pacific people consider themselves over-researched (Cheer et al, 2002). In response to these concerns some institutions have become concerned at the way research is conducted on Pacific people and have attempted to ensure that research on Pacific peoples is *for* Pacific peoples.

1.6 Health Research Council Pacific Research Guidelines

The Health Research Council of New Zealand (HRC) has produced a set of guideline to assist health research with Pacific peoples living in New Zealand. These guidelines provide a foundation for ensuring that research is not only *on* Pacific peoples but more importantly *for* Pacific peoples in order to improve their quality of life in New Zealand. Health research cannot just be descriptive; it must also provide outcomes to improve Pacific people's health. The guidelines insist that Pacific health research requires a Pacific world view as a reference point. Furthermore, the guidelines outline important Pacific principles for forming and maintaining ethical research relationships

³ Estimate at mid 2001 prepared by the South Pacific Commission Demographic/Population programme

with Pacific peoples. The principles of respect, meaningful engagement, reciprocity, utility, rights, balance, protection, capacity building, participation and cultural competency (Health Research Council, 2004), which inform this thesis, are summarised in more detail in Chapter 4.

1.7 The researcher

The links between the researcher and the research focus of this thesis warrant explanation. I am a young New Zealand born Samoan woman. Even though I have lived most of my life in New Zealand I still travel back and forth between Samoa and New Zealand regularly. Thus, both places are home to me. For my parents, although I have grown up in New Zealand it was important to them that I learned *fa'asamoa* or the Samoan way. Therefore, I have always been both a participant and observer in Samoan cultural ceremonies and have learnt some of the traditional way of some practices such as the *siva* or Samoan dancing. I have been an active member of my church congregation since I can remember which has been immensely helpful in retaining fluency in my mother tongue throughout the years. Thus I can speak, read and write Samoan fluently. The implication of this dual sense of home (Auckland and Samoa) will be considered more fully in Chapter 4.

The dual sense of my 'samoan-ness' has had a bearing on the thesis in a number of ways. Most graphically, it led me to focus in the first instance on TB among Samoan people in Samoa and Auckland although any Pacific TB patients in Auckland were considered candidates for inclusion in the study.

1.8 Thesis outline

This first chapter has provided an overview of the thesis topic, outlining why the study of TB for Pacific peoples is important and necessary as well as providing a brief overview into the epidemiology and treatment of TB.

In Chapter 2 TB trends and rates over the last 10 years for the Pacific peoples in particular and the Auckland population more generally, are reviewed. This is to illustrate the distribution and progression of TB across the Pacific and in Auckland. The chapter discusses the transnational nature of Pacific communities and migration

patterns into Auckland since the 1950s. Using the notion of recursive place/location, an analysis of Pacific identity and place is outlined. This analysis explores not only how Auckland has impacted on Pacific migrants' identity but also how Pacific identity has impacted on Auckland's landscape by analysing Auckland as a Pacific 'ethnoscape' (Appadurai, 1997).

Chapter 3 explores Pacific health perspectives and presents a Samoan health framework. In this chapter I provide a framework which integrates the health themes that are most common around the Pacific such as viewing health as a socio-ecological concept. The Samoan health framework provides a foundation for understanding the diagnosis process, causation and agents of illness and treatment for illness from a Samoan perspective. The chapter then concludes with a discussion on the impact of migration on Pacific people's health in Auckland and vice versa.

In Chapter 4, I outline the research process in which I describe the approach and methods that were incorporated and utilised during my fieldwork in Auckland and Samoa. The first part of the chapter revisits my positionality as a young Pacific woman conducting Pacific research and the implications that this had while conducting fieldwork. Next, I outline the qualitative methods that were used for this thesis. A brief review of my experience undertaking with researching in Samoa is provided. This review is then followed by a summary of my fieldwork in Auckland. Lastly, I introduce my participants with a brief description of their age, ethnicity, gender and TB status.

Chapters 5 and 6 consists the analysis of my fieldwork. Chapter 5 outlines some of the major themes that emerged through the analysis of the participant's health narratives. I begin with an analysis of the participants' diagnosis process. This is then followed by the consideration of their perceptions of TB by understanding participants disease-related fears as well as understanding their past experience or health culture (van der Oest, 2005) relating to the disease. The chapter concludes with an analysis of medical pluralist themes where the participants' beliefs about health, western medicine, traditional medicine and their relationship with health professionals are provided.

Chapter 6 discusses themes associated with social networks and identity. This chapter begins by reviewing the transnational nature of the participants and their migration histories. Next is an analysis on which social networks, if any, when they had been utilised and why. The chapter concludes with an analysis of young Pacific people's identity in Auckland and how western science and traditional medicine has impacted on their health beliefs.

In conclusion, Chapter 7 provides a summary of the study findings and addresses some of the questions around why Pacific peoples in Auckland have such a high TB rate and some of the social stressors that can activate the disease. It also presents some observations as to whether the findings of this study support other claims in relation to Pacific peoples, and migrants in general, and their association with TB are also presented. Suggestions for further study to enhance the understanding of the social determinants of TB and the lived experience of Pacific TB patients are then presented. The chapter concludes by outlining practical implications for policy and practice.

Chapter 2

Tangata Pasifika: Pacific peoples and TB

*“Our destiny is shaped by our continuity of consciousness
which has its roots in our memories of thousands of years of
existence in Te Moana-nui-a-Kiwa (Pacific Ocean)...”*

Cletus Maanu

2.1 Introduction

It is imperative for this study that the context of Pacific migration is explored in order to understand the influences and changes that migration has imposed on Pacific people’s cultural identity. This is important as identity informs our explanatory models and encroaches on how we perceive things and how we behave. To fully understand the resurgence of TB in the Pacific it is necessary to determine the distribution and variance of TB across the region and which populations are affected the most. The chapter therefore begins by reviewing past studies of TB to establish what research has been conducted and how effective these studies have been in increasing our knowledge and understanding of the ecology of TB in the Pacific. The chapter presents statistical data to illustrate the geographic distribution of TB across the Pacific, followed by a review of the epidemiology of TB for Pacific peoples in New Zealand. High rates of TB have long been attributed to the poor socio-economic status of Pacific peoples in Auckland and this assertion is explored and leads into a discussion on Pacific migration to Auckland.

The second part of the chapter deals with Pacific migration and the transnational nature of Pacific migrants. By reviewing the migrant history of Pacific peoples in Auckland I analyse the stresses, obstacles and challenges caused by migration. However, the Pacific community has matured so that now Auckland comprises of more New Zealand-born Pacific peoples. This growing group of Pacific people faces many identity challenges as children of migrants in a western urban society. Thus, the

relationship between identity and place is explored by examining Auckland as a Pacific ethnoscape.

2.2 TB and Pacific peoples

2.2.1 Research on TB in the Pacific

Recent health research on Pacific peoples in New Zealand has concentrated mainly on non-communicable diseases such as diabetes, cancer and cardiovascular disease. This trend is mainly in response to the alarming rate in which non-communicable diseases have affected Pacific people's health patterns in terms of morbidity and mortality over the last 30 years (Bathgate, 1994; Foliaki and Pearce, 2003). Thus, the focus on Pacific people's health in New Zealand has shifted away from communicable or infectious disease such as TB.

A small number of sporadic case studies relating to Pacific people and TB have been documented. These studies have not taken a disease ecology approach where both biomedical and social aspects are assessed. However, most of the studies have looked at some of the social aspects regarding TB such as Bava's (2005) review on the history of TB in the Pacific. One of the first TB case studies conducted in the Pacific was a case series of TB in Micronesia by Mahmoudi and Abraham (1996). The study was conducted to describe the demographic, clinical and bio-medical characteristics of TB patients in Micronesia. In 1994, Micronesia had a TB case rate of 107 per 100,000 which was approximately 10 times higher than that of the national average for the United States (US). The study highlighted the need for more research and information on TB on Pacific people especially when it was known that there was a disproportionately high number of TB cases for Pacific peoples in the US.

Rudoy's (1996) article on TB and hepatitis in the Pacific highlighted the risk factors for TB such as overcrowding and malnutrition, which partially explains the high rate of TB for Pacific peoples. Further the article illustrated the difficulty in eradicating TB due to the transnational nature of Pacific communities making TB more than just a local problem. This is indeed an important deduction for Pacific peoples that merit a closer examination of TB and health, and migration. There have been other studies

that have researched attitudes towards TB in the Pacific. Ah Ching et al (2001), for example, conducted a study on attitudes regarding TB among Samoans in Hawaii and highlighted the high incidence of TB in Pacific migrants in the US. The study focused on a small group of Samoan migrants. However, it is unclear how many of those who participated actually had the TB disease. Ah Ching et al (2001) looked more at the social and physiological implications of TB and found that stigma and marginalisation is still associated with TB for this Samoan group. As well, the study found that although patients did not seek traditional medicine to directly cure the illness, they still used traditional medicine to help the immune system and to complement western treatment.

The most recent study on TB and Pacific peoples was the multicultural research on TB based in Waikato, New Zealand, conducted by van der Oest et al, (2005). The study explored the diversity of opinions amongst different refugee and minority group representatives about TB and examined the provision of services and their effectiveness within the Waikato Health District. The study found that communication barriers and difficulties in accessing health care due to cultural and structural barriers and the absence of health services oriented towards these population groups are important impediments to TB control in the Waikato district. This is one of the few studies which examine TB from a purely socio-ecological approach. The biological pathways of TB are already well established. Therefore for health workers, the most pertinent question, considering that TB infection is necessary but not sufficient for TB disease, is: *what are the socio-determinants of TB and, more importantly what intervention is required to prevent the progression of TB disease?*

2.2.2 Tuberculosis trends across the Pacific

The aforementioned studies have been in response to the resurgence of TB in the Pacific. However, the distribution and prevalence of TB across the Pacific varies. In some countries such as Tokelau and the Cook Islands, for instance, TB is almost non-existent.

Conversely, TB in the Western Pacific is rampant. As highlighted in Table 2.1 below there is a high prevalence of TB in Western Pacific countries, where they had the highest number of TB cases were reported with Kiribati and Papua New Guinea showing 324 and 322 rates per 100,000 for 2003 respectively.

Table 2.1: TB rates per 100,000 for the Pacific from 1995-2005

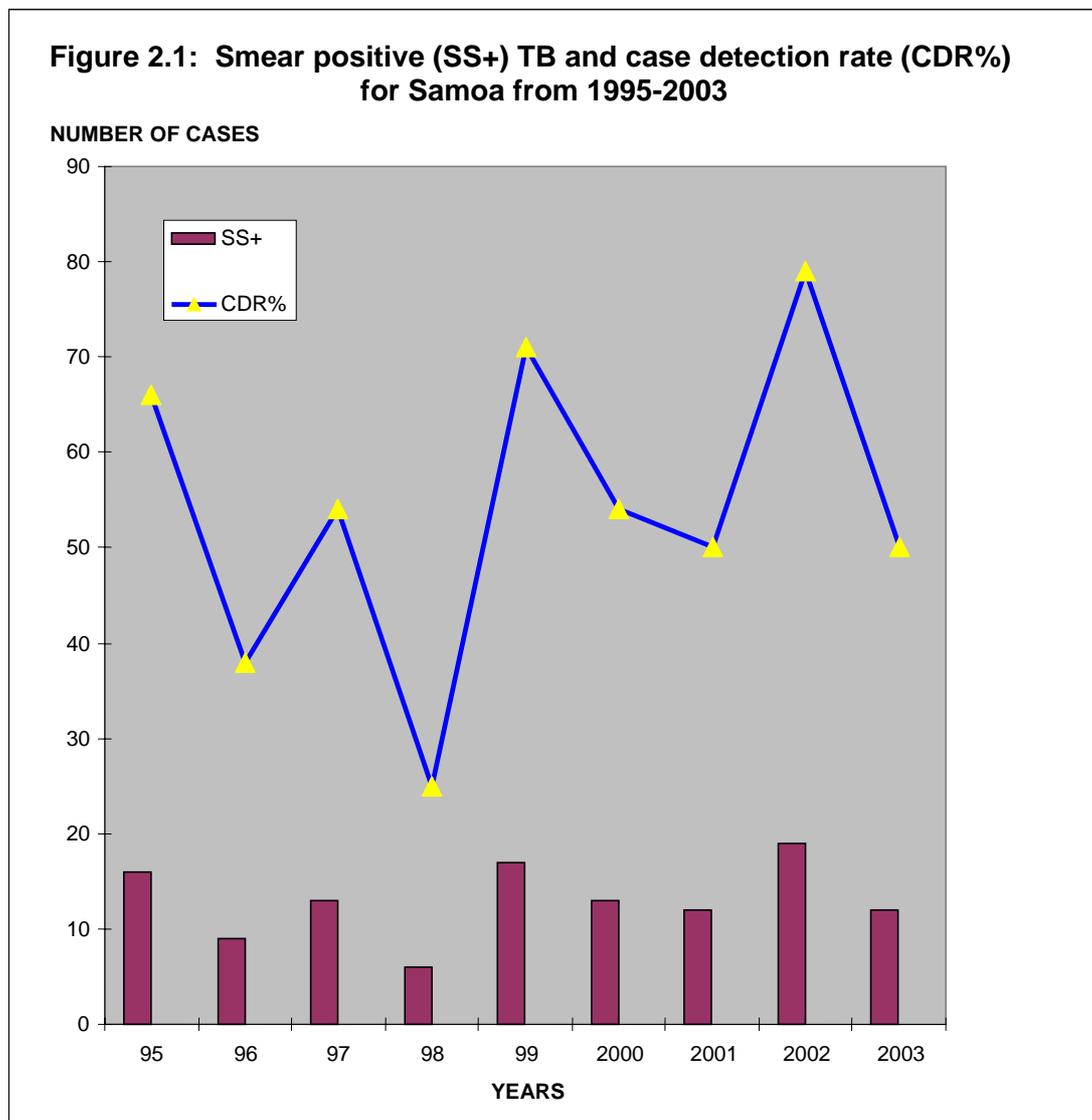
	1995	1996	1997	1998	1999	2000	2001	2002	2003
American Samoa		0	11		7	5	5	3	5
Cook Islands		0	0	5	16	11	11	5	0
Fiji	26	26	22	21	24	18	22	18	21
French Polynesia		39	41	46	41	27	26	27	20
Kiribati		414	40	339	306	300	222	227	324
Marshall Islands		122		98	81	67	108	97	113
Micronesia	161	117	99	115		85	88	117	91
Nauru					17	33	24	39	23
New Caledonia	45	53			37	44	28	29	16
New Zealand	9	10	9	10	12	9	10	9	10
Niue	0	95	0	0	49	0	0	203	0
Northern Mariana Islands	87	88	153	152	99	107	79	70	57
Palau	111	28	83		170			55	44
Papua New Guinea	171	106	161	222	251	227	291	95	322
Samoa	27	19	19	13	18	25	13	18	15
Solomon Islands	94	77	80	72	68	69	65	55	61
Tokelau	131	0			0	0	0		0
Tonga	20	22	21	30	22	24	12	28	15
Tuvalu	378			181	139	157	155	124	283
Vanuatu	46	71	101	95	61	77	87	49	49
Wallis and Futuna Islands	43	57	98					130	102

Source: Western Regional Office for WHO, 2005

For the southern Pacific countries, the larger island nations such as Fiji, Tonga and Samoa demonstrate similar rates of TB disease. When compared to New Zealand these figures are noticeably higher.

2.2.3 Samoa's TB campaign

Samoa recently began an aggressive campaign to spread awareness of TB and to assist in TB control. Figure 2.1 below, demonstrates that one of the problems for public health in Samoa is case finding. Thus the campaign was established to help with case detection. The campaign includes television and radio commercials as well as brochures that highlight the importance of seeking western medical advice as soon as symptoms of TB appear. The advertisements outline mechanisms for the transmission of the disease as well as addressing the issue of stigma by emphasising that TB is no longer the same disease that was feared in the 1950s. Campaign advertisements and health promotional messages explain that TB is now curable and is a worldwide phenomenon.



Source: *Lameko, 2005*

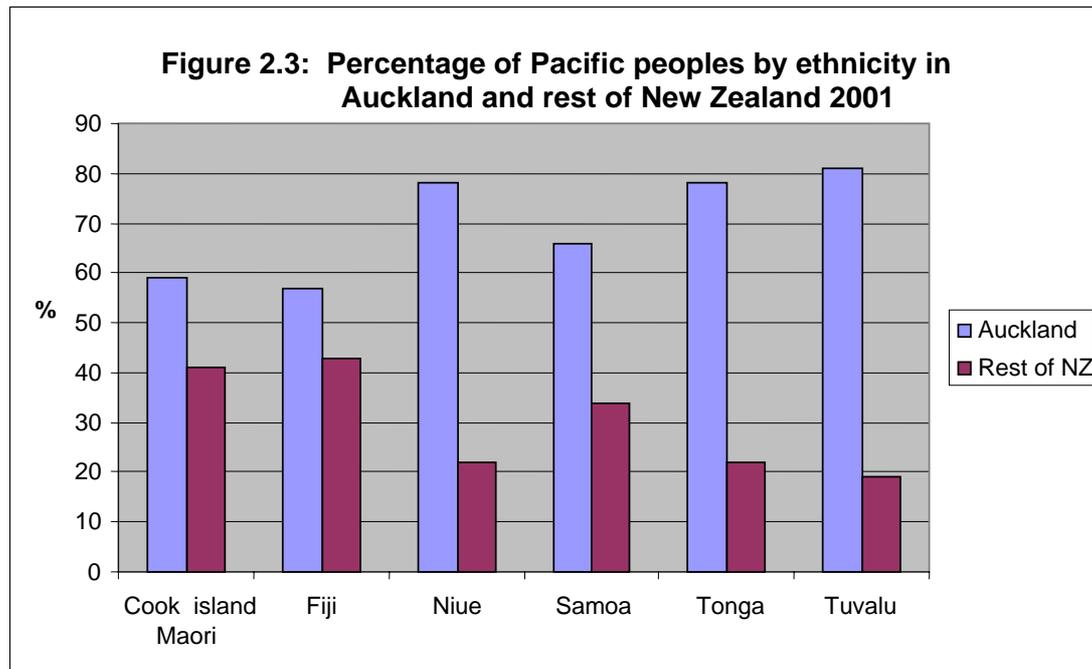
Administering DOT and contact tracing is difficult in Samoa. Unlike New Zealand the only roads that are formally named are the main arterial roads. The public health service therefore often relies on descriptive directions for contact tracing and administering DOT. Giving descriptive directions is the norm and way of life in Samoa which can be time-consuming if the area is not well known. The majority of roads are also unpaved, thus the public health service uses four wheel drives. The only problem with this is that these vehicles also have large Ministry of Health logo's on the side (as shown in the picture below), thus eliminating any hopes of privacy and discretion for the patients. The other challenge in trying to locate contacts is that people are frequently moving between the different households of their kin. This propensity becomes another challenge and a time-consuming exercise for the public health service.

Figure 2.2: Ministry of Health Vehicle in Samoa



2.3 TB and Pacific peoples in Auckland

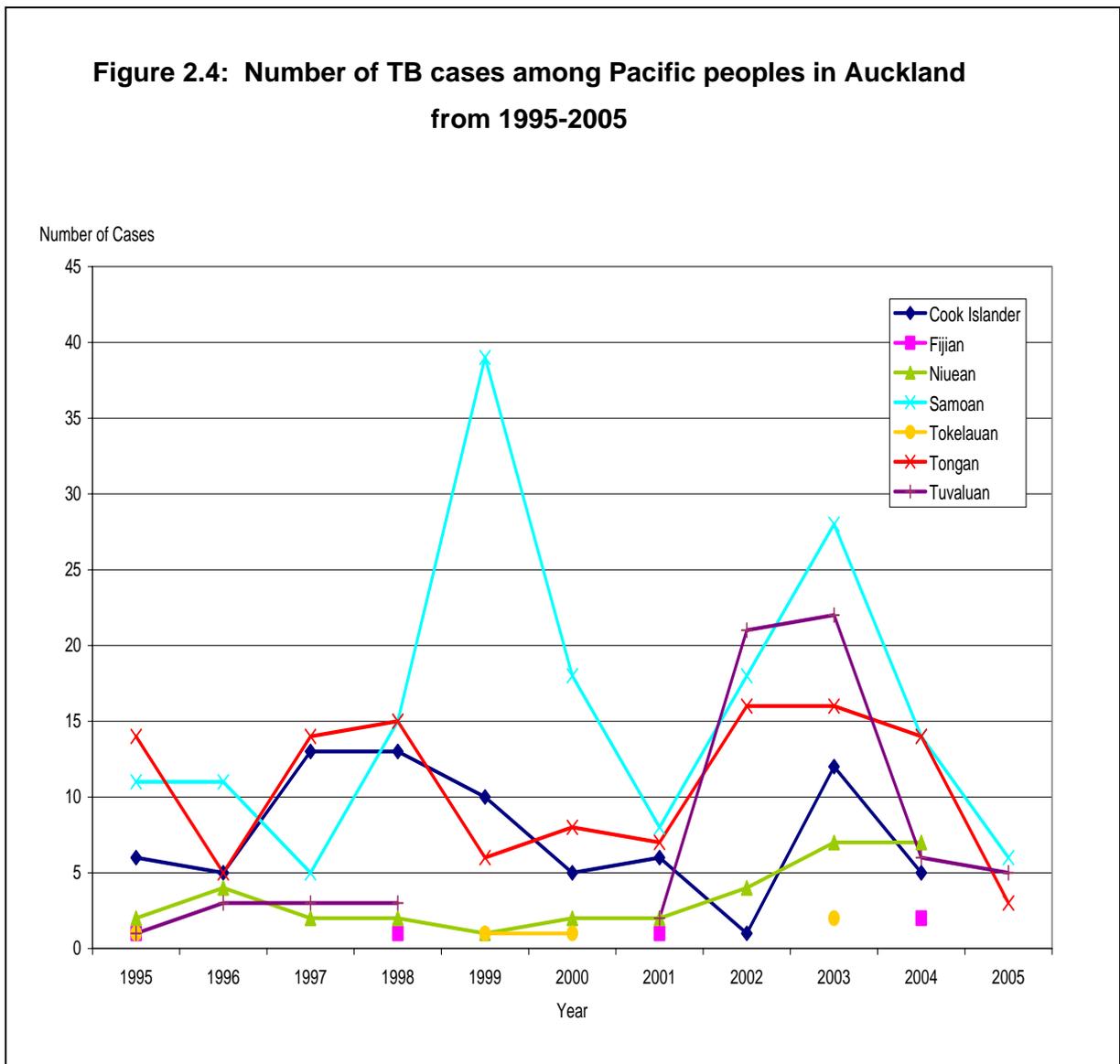
In New Zealand, Pacific peoples are highly concentrated in Auckland where, in 2001, 67% of the total Pacific population reside compared with 11% nationally. The graph below (Figure 2.3) shows the percentage of Pacific peoples by ethnicity residing in Auckland, compared with the rest of New Zealand.



Source: Statistics New Zealand, 2001

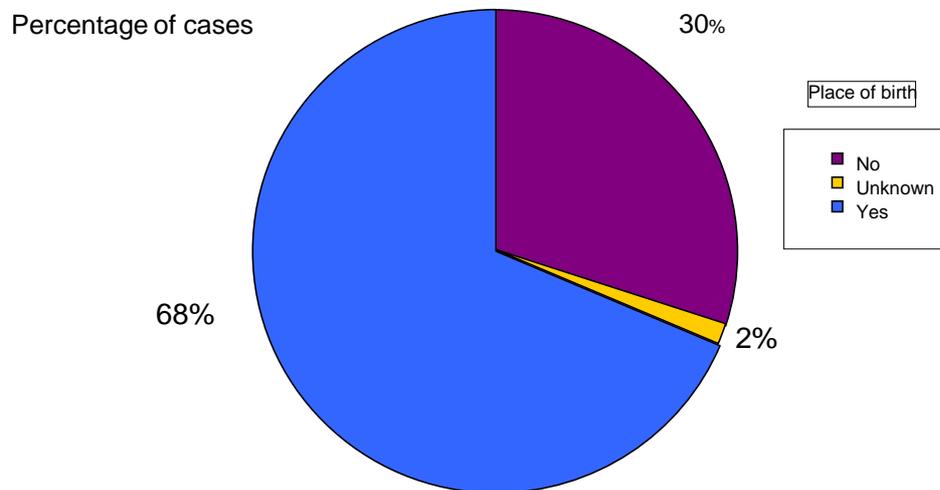
As the graph in figure 2.4 shows, the Samoan community has the highest number of TB cases for Pacific peoples in Auckland. However, Samoans make up over half of the Pacific community in Auckland. The high peak of TB for the Samoans in 1999 is attributed to the outbreak that occurred in an Auckland church group. According to Thornley (2005) Pacific peoples are more likely to acquire TB transmission from within New Zealand than any other ethnic group. The likelihood of identifying the source of TB through contact tracing is higher among Pacific peoples than any other population group.

Figure 2.4: Number of TB cases among Pacific peoples in Auckland from 1995-2005



Source: Thornley 2006

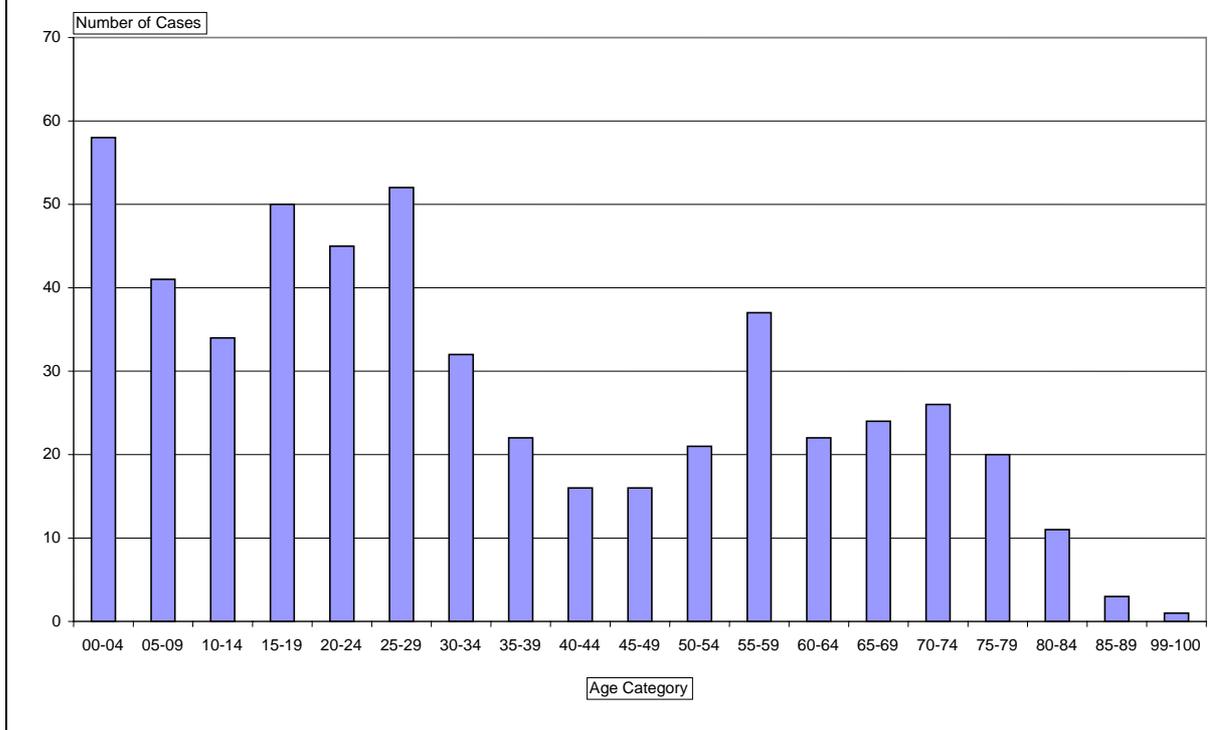
Figure 2.5: Percentage of Pacific peoples with TB in Auckland born in New Zealand and Overseas from 1995-2005



Source: Thornley, 2006

Figure 2.5 (above) shows that between 1995 and 2005, two thirds of Pacific peoples in Auckland who had TB were born outside of New Zealand. However, this graph does not depict how long the migrants were in New Zealand before they actually became afflicted with TB disease. From 1999-1995, 45% of migrants, including Pacific migrants had lived in New Zealand before notification, suggesting that TB infection occurred whilst in New Zealand rather than overseas (Carr et al, 2001). This matter, of migrants and time of arrival before the onset of TB is discussed further in Chapter 3.

Figure 2.6: Pacific TB cases in Auckland by age group from 1995-2005



Source: Thornley, 2006

Figure 2.6 (above) shows that TB mainly affects people in the younger age groups more than the elderly⁴. The so many children under five years of age had TB is of grave concern especially when Pacific neonates born in Auckland are given the BCG vaccination. The high rates of TB for the under-five age group may reflect that those with TB may be infants who have recently migrated with their families to New Zealand. The high rates of TB among the age groups of 15-29 years can be attributed to the incidence of outbreaks such as the 1999 outbreak that involved an Auckland church group. Two similar outbreaks in 1998 involved two separate schools and a household. These three outbreaks resulted in 36 TB disease cases (Carr et al, 2001).

Because of the high rates for Pacific populations and the largest proportion of those with TB disease being born overseas (Carr et al, 2001) they have been the only ethnic group singled out in the *Guidelines for TB control 2003* in which the Ministry of Health (2002) clearly states that persons who have increased risk of TB are

⁴ A full breakdown of age group and ethnicity is available in the appendix.

- Those with recent TB infection (within the last two years)
- Close contacts of people with TB
- People with HIV or who are immunosuppressed
- Persons recently arrived from high incidence country
- Elderly
- Children exposed to high risk adults
- Pacific peoples

“Pacific peoples” is the only ethnic category deemed to be at risk of TB. As lower socio-economic status is a major social stressor, and part of the ecology of TB, I next review socio-economic conditions for Pacific peoples.

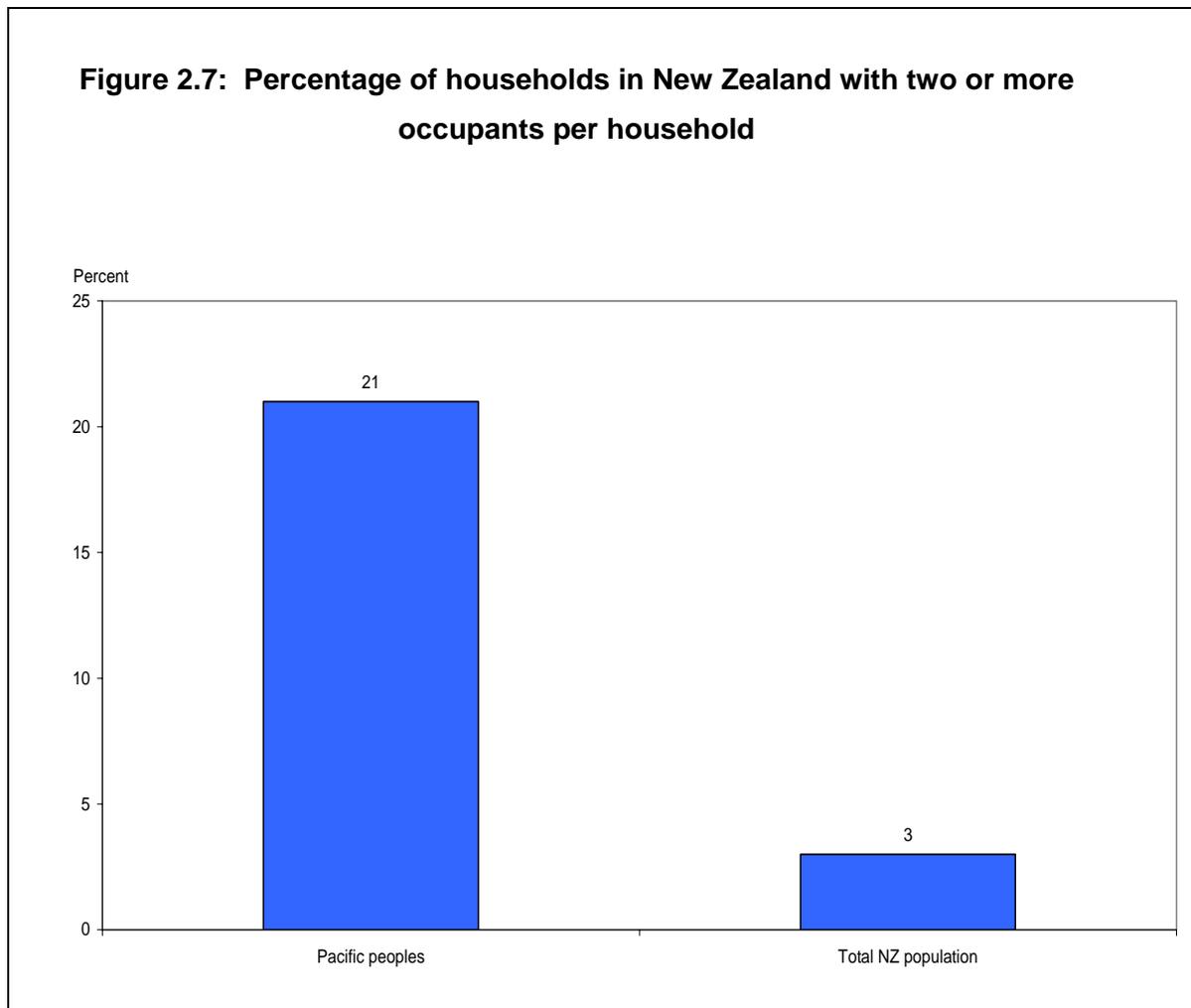
2.3.1 Socio-economic status

The socio-economic status of Pacific peoples has been well documented. It has been well established that Pacific peoples are overrepresented at the lower end of the socio-economic spectrum (Tukuitonga and Finau, 1997; Ministry of Social Development, 2004; Statistics New Zealand, 2003). Further, in 2003 the rate of unemployment for Pacific peoples was 7.9% compared to 4.6% for the total population (Ministry of Health, 2004). The 2001 census showed that Pacific peoples were also overrepresented in lower paid employment so that the median annual income of Pacific peoples in the 2001 census aged 15 years and over was \$14,800 (Southwick, 2005), compared with \$18,600 for the total population (Ministry of Pacific Islands Affairs, 2002).

Pacific peoples are also over represented in state housing and rented accommodation and occupy the poorest and most insalubrious housing in Auckland (Cheer et al, 2002). This trend is also evident when examining neighbourhood deprivation where 22% of Pacific peoples live in decile 10 areas as defined using the NZDep2001⁵ (Salmond and Crampton, 2002). In 2001 the average number of occupants for all Pacific households was 5.4 compared with 3.5 for New Zealand as a whole (Statistics New Zealand, 2002).

⁵ NZDep2001 measures neighbourhood deprivation with 1 being the least deprived and 10 being the most deprived.

Moreover as the Figure 2.7 graph 20%, of Pacific peoples live in homes where there are more than two occupants per bedroom (Ministry of Health, 2004).



Pacific peoples tend to live in overcrowded conditions and it is not unusual for extended family to live under one roof. But extended living is not only the result of poverty and financial difficulty; it is also a source of social support and material assistance which can contribute to better health. However the health costs outweigh the social benefits for extended family living in small, poorly ventilated housing (Milne and Kearns, 1999).

These living conditions provide a favourable environment in which illness and diseases, such as, TB thrive and spread. Numerous studies have been conducted which emphasise the relationship between TB and overcrowding (Acevedo-Garcia,

2000; Curtis, 2004, Hawker et al, 2005). Pacific peoples' transnational culture complicates the issue of overcrowding as visitors often visit for long periods of times. Recent migrants are also more unlikely to find accommodation before migrating and so on arrival in New Zealand, they may temporarily live with relatives before finding a place of their own. Therefore, for TB control it is important that these overcrowded housing situations be rectified in order to provide healthier and safer homes. The 'Healthy Housing' and other similar programmes are helpful innovations (Housing New Zealand Corporation, 2005).

2.4 Transnationalism

Transnationalism is not a recent phenomenon although it has recently become a dominant one in terms of global migration patterns. For the purpose of this thesis, transnationalism is likened to a mode of cultural reproduction and a reconstruction of place or locality for migrant groups (McEwan, 2004) and is helpful in understanding the complexities of identities and lived experiences. A 'transnational' can be viewed as a migrant whose cultural identity is impacted on by values, ideas and customs of the nation of origin as well as the host nation. Within geography transnationalism has tended to be influenced by economic globalisation. A gap in the transnationalism literature in respect to cultural globalisation and the connections between cultural identity and mobility and space or place is currently being addressed (McEwan, 2004). This thesis represents a modest contribution

Large numbers of transmigrants mainly affect certain cities, which have become known as gateway or world cities (Knox, 1995) (for example Los Angeles, Sydney, San Francisco and Auckland). For Pacific peoples these gateway cities are readily accessible through their own national airline carriers. For example all major Pacific airline carriers (for example, Fiji's Air Pacific, Vanuatu's Air Vanuatu and Samoa's Polyblue) fly directly to Sydney and Auckland. Also Tahiti's national carrier Air Tahiti Nui flies directly to Los Angeles. Transnationalism and migrants therefore become a pertinent issue for these cities. Gateway cities face issues over the contestation of space and place as well as developing sites of special kinds of cultural spaces, identities, text, discourses and metaphors (Knox, 1995). These cities become highly politicised especially when migrant groups become more concentrated in

certain parts of a city. This concentration facilitates social processes such as social cohesion.

Social cohesion can be viewed in terms of what Boal (1987) terms ‘a constructive mechanism’ whereby social cohesion functions as a way to provide mutual support, establishing networks for commerce and enterprise, and to preserve cultural identities. One institutional way in which migrant groups preserve cultural identities is through their religion. Christian religion has been embedded within Pacific cultures, so much so that often the Pacific has become synonymous with Christianity (Macpherson, 2004). In moving to new homelands churches have replaced the village as the church became the nexus for social organisation (Macpherson, 1997). Christianity and the church became the foundation for community development and solidarity whereby parishes have become the focus of the members’ social and political lives (Macpherson, 1997). This process is especially evident with Pacific Peoples in Auckland where large elaborate churches have been built since the 1970s throughout metropolitan Auckland. In almost every suburb there is at least one Pacific Island church of different denominations (as Figure 2.8 on the following page illustrates some of the Pacific churches around Auckland). From the 2001 census 80% of Pacific peoples acknowledged belonging to a religion compared with 60% for the nation (Ministry of Health, 2004). Even as the Pacific communities in Auckland have matured, the church is still of great importance in Pacific peoples lives as the text box below, of my own experience illustrates.

I am an active member of the Sulu of le ola congregation at Manukau, one of the nine congregations of the Congregational Christian Church of Samoa (CCCS) South Auckland ‘Pulega’ or parish. Our congregation with 95 members is relatively small compared to the other congregations, some of which have close to four hundred members. The (CCCS) is the largest denomination in Samoa and is also one of the largest Samoan denominations in Auckland. It is a very structured organisation where the Auckland CCCS churches are divided into two main geographical divisions; Central Auckland and South Auckland. These two District Branches are further subdivided into ‘pulega’ or parishes where South Auckland has five.

Figure 2.8: Pacific churches in Auckland

2.4.1 Homelands

Pacific churches in Auckland pictured clockwise, Samoan church in Ponsonby, Cook Island church in East Tamaki, Tongan church in Otara and Samoan church in Papatoetoe. Transnationalism is a two way dynamic thus homelands are just as much affected as host cities. In 1997 Bedford estimated that there were more than half a million people of Pacific Island descent living outside of the Pacific (cited in Friesen, 2000). This is an enormous population relative to resident populations of Pacific island nations. In some cases; some ethnic populations in Auckland outnumber the home population. For example there are 1,900 Niueans living at home compared with 20,148 in New Zealand. Essentially, there is almost 10 times more Niueans in New Zealand than at home (Statistics New Zealand, 2003).

Past studies on transnationalism and the Pacific have dwelt on the reliance of home nations on remittances and the distortions that out migration, aid and remittances have on the local economy (Bertram and Watters, 1986; Marsters, 2005). Emigration out of the island nations does pose a serious problem for governments in terms of domestic development as the majority of migrants are within the working age groups, .remittances and aid in the development of small family business enterprises especially in relation to the tourism market (Connell and Conway, 2000; Marsters, 2005).

Return migration is an important feature of Pacific migration and transnationalism (Connell and Conway, 2000). The main motivation for leaving the island nations is to seek better opportunities in terms of employment and education (Southwick, 2005). However, once children have grown up and have finished their education some Pacific migrants return home to retire. Return migration became a viable option when the New Zealand superannuation policy in the 1990s allowed living overseas to gain

access to their pensions in the islands. Return migration of pensioners, however, impacts on the health services of home countries.

2.4.2 Cultural social reproduction

As a cluster of migrants regroup in host cities they inevitably try to recreate their histories and experience of place from their homelands (Knox, 1995). For ethnic migrant groups solidarity in new settings arise from either a real or imagined common history or ancestry leading to the cultural creation of communities (Nagel, 1994). This process is especially important for pan-ethnic groups as the dominant ethnic group tends to mould migrant ethnic groups into one category (Spoonley, 2001). Ethnic conceptions of place, whether they reflect nostalgia or are part of a coping mechanism, are physically transforming landscapes. This set of processes is evident with the influences of Pacific identity within the Auckland landscape to the extent that there is now a Pacific ethnoscape in Auckland. This ethnoscape will be discussed in more detail later in the chapter.

Cultural retention is an ideal and important marker of distinction for transnationals. Increasingly, the retention of culture is mediated within their new cultural context (McEwan, 2004). People retain and produce their ethnic and cultural identities in landscapes and place through different physical mediums such as dwellings and gardens (Duncan and Lambert, 2004). Landscapes influenced by transnationals ultimately reflect a new hybrid of settler and migrant cultures (Knox, 1995). The ubiquitous presence of transnationals in a landscape leads to a change in architectural styles, consumption patterns, music, art and fashion that over time become normalised as they overtake the preceding landscape.

2.4.3 Ethnic enclaves

In some parts of gateway cities a new situation has developed over time whereby a transnational population becomes the dominant group in a landscape and so ethnic symbols in this landscape becomes normalised. This situation or landscape has been termed 'ethnic enclaves' (McEwan, 2004; Nagel, 1994). The most common example of ethnic enclaves in the literature is the various Chinatowns in cities such as Vancouver and Atlanta (Duncan and Duncan, 1988; Stewart, 1999). The ethnic

enclave can be described as creating homeland landscapes in new settings whereby representations of homelands become overwhelming in comparison to other surrounding areas. This creation or representations of homelands can be constructed in a way that is unique to the migrants and can differ significantly to homelands as transnationals only incorporate and adopt those things they wish to be incorporated and ignore the rest. Homeland representations are often ignored by dominant groups and are only noticed by those with intense knowledge of the ethnic cultures.

Landscape modifications can range from the subtle, such as growing specific plants (for example taro in the case of Pacific people) to being blatantly obvious, such as the formation of ethnic food halls within a landscape (Stewart, 1999) as well as institutions such as Pacific *fale*-style churches and services like the Pacifica Healthcare Clinics in the suburbs of Otara and Henderson in Auckland which cater for Pacific Peoples. The landscape of healthcare for Pacific peoples provides an interesting interpretation of the changes that have taken over time in relation to Pacific people's access to healthcare. When first migrating to New Zealand, Pacific peoples brought with them their own methods of healing and healers. Thus Pacific peoples used their traditional healers in lieu of visiting western medical clinics. This was mainly due to language difficulties as well as structural barriers in accessing health care. Over time, the poor health status of Pacific peoples became a worrisome concern for administrators. In response to the health concerns of Pacific peoples, there has been a new wave of healthcare services which are provided by 'Pacific for Pacific'.

Ethnic enclaves present an example of landscapes of togetherness or otherness where the landscape can be viewed as an ethnic group coming together and creating a community for the purpose of identity and solidarity (Atkins et al, 1998). Conversely ethnic enclaves can be viewed as being marginalized and representations of the 'other' through both structural and economic forces. Either way, transnationalism and ethnic enclaves have created a state of change where landscapes and place have been altered through the transplanting of some different cultural ideals and value systems that have been renegotiated in order to correspond with their new context. At the same time, however, place itself impacts on transnationals' identity. Eyles (1985) describes sense of place as involving a recursive relationship between actual or literal

places and 'place-in-the-world' (cited in Gesler & Kearns, 2002). Gesler and Kearns (2002) explain that 'place-in-the-world' "refers to the self or externally ascribed status that comes from association with, or occupation of, particular sites" (2002, p.5). Thus transnationals' construction of place both physically and ideologically involves a recursive relationship between place and identity.

2.5 Auckland and Pacific peoples

2.5.1 Migration patterns since the 1950s

Considerable migration from the Pacific occurred after World War 2 during New Zealand's economic boom so that by 1973 40 percent of temporary migrants were of Pacific descent (Macpherson, 2002). Pacific migrants filled the gaps in semi-skilled and unskilled labour. This situation led to the concentration of Pacific migrants in urban areas such as Auckland, as these were the locations of employment, industry and opportunity (Pulotu-Endemann and Spoonley, 1992). Further, social processes such as chain migration exacerbated the urbanisation of Pacific migrants. From the 1980s New Zealand began to experience an economic down turn and so the situation of a shortage of labour was completely reversed as New Zealand faced the undesirable circumstance of increasing unemployment. Despite this change, Pacific migration did not cease as would be expected, but still continued at a reduced rate (Pulotu-Endemann and Spoonley, 1992).

The reason for this continued migration was due to social factors, as well as economic and political circumstances in the Pacific. New Zealand, although facing an economic downturn, still represented an ideal homeland for Pacific peoples as New Zealand still had far more opportunities and future employment prospects than the Pacific Islands nations. This was especially true in terms of schooling and education (Pulotu-Endemann and Spoonley, 1992). This recognition in part explained continued migration post-1981 during the peak of New Zealand's economic downturn. Another reason was due to kinship ties as Pacific families began reuniting in Auckland. Kinship ties and affiliation are regarded highly in Pacific societies and arguably represent the pinnacle in Pacific value systems (Macpherson, 2002; Spoonley, 2001). Thus, Pacific migrants who had immigrated first began building foundations in order

for family members to eventually join them. Family members were not limited to immediate family but also included the extended family members such as grandparents, aunt, uncles and cousins.

The period between 1980 and 1990 signifies a dark and tumultuous period for Pacific migrants in New Zealand. Economic pressures had created a situation where migrants from the Pacific, once warmly welcomed by the state, were now subjected to racism and structural practices reflecting racial overtones such as the infamous dawn raids (Macpherson, 2002; Spoonley, 2001). 'Dawn raids' was a practise utilised by the National government in the 1980s to crackdown on overstayer migrants. This practice, particularly with regards to Pacific peoples, involved immigration officers and police invading homes of Pacific peoples in the early hours of the morning (Anae, 2004). Some in New Zealand began to fear and detest migrants, especially those from the Pacific who were more noticeable in the demographic landscape. Migrants were regarded as stealing jobs from New Zealanders and creating unnecessary unemployment for the 'typical' (that is, Pakeha) New Zealander. This situation led to racial violence and conflict as Pacific migrants bore the brunt of the consequences of the economic downturn (Anae, 2004).

The government claimed that, at the time, there were approximately 9500 illegal immigrants in the New Zealand. What was not acknowledged was that Pacific people accounted for less than a third of the illegal immigrants. Pacific people were also the only ones prosecuted and deported for immigration violations (Southwick, 2005). The irony is that throughout New Zealand's history and even in the present the majority of migrants have come from Anglo-Saxon nations, more specifically from Britain. So, in comparison, Pacific migration was still relatively small compared to European migration. At any rate, the situation worsened for Pacific peoples during this period as economic and structural forces began dictating the location of Pacific peoples. During the 1970s, for instance, Pacific peoples were mainly concentrated in the inner city suburbs of Grey Lynn, Newton and Ponsonby. By the 1980s this changed as Pacific peoples underwent a massive process of suburbanisation such that Pacific peoples are now concentrated in suburbs such as Manukau, Otara and Mangere (Pulotu-Endemann and Spoonley, 1992). This intra-urban migration was prompted by housing market dynamics including the re-valuing of central city living by the Pakeha majority

Pacific transnationals are an important demographic and social feature in Auckland's landscape and their presence in Auckland's cultural landscape has been progressively mounting. For Pacific migrants and their families Auckland continues to be the destination of choice both temporarily and permanently (Anae, 2004). The growth of New Zealand's Pacific population from the 1940s to the 1970s was migration-based and since then the growth has been domestically driven (Ministry of Health, 2004). Presently, there are more than 231,801 permanent residents of Pacific descent in New Zealand and over half reside in Auckland (Manukau City Council, 2003). Interestingly 58% of people who identified as of Pacific descent were born in New Zealand. The identity implications of New Zealand born Pacific peoples and differences between island-born and New Zealand born Pacific peoples presents an important issue surrounding health-seeking behaviour and the utilisation of traditional medicine (Anae, 2004; Macpherson, 2002).

2.5.2 Pacific identity and place

The term 'Pacific peoples' represents a pan-Pacific identity. This pan-Pacific identity was created through the New Zealand media, political discourse and public imagination to encapsulate the diverse range of ethnic groups from the Pacific region as one group. This pan-Pacific dominance has taken precedence over specific ethnic identities in relation to national issues. Further hegemony of the pan-Pacific identity hegemony is perpetuated through increasing inter-marriage among members of Pacific ethnic groups to the extent that the number of Pacific peoples are of mixed blood is becoming ever more significant (Macpherson, 2002).

Second and third Pacific Island generations have a different identity to that of their migrant parents and grandparents (Macpherson, 1997). These generational differences and others reflect the transnational nature of Pacific communities and are not just confined to Pacific peoples but to other transnational communities throughout the world (Spoonley, Bedford & Macpherson, 2003). The first Pacific migrants had vivid memories and strong associations with their homelands so that in reality the

connection to New Zealand was not viewed as 'home' as such but rather as a new setting (Anae, 2004). Members of second and third generations that have lived and have been brought up in New Zealand have a different view on their original homelands and therefore identify Auckland as home. But in still maintaining traditions and cultures these new generations have created a new milieu reflecting the conditions in which their identity was fabricated in the Auckland landscape.

The structure of the worldview for Pacific youth in New Zealand illustrates the local outcomes of transnationalism whereby politics of identity and identity positions are a combination of both Pacific and western culture. Macpherson (2004) describes this outcome as a "'sub-culture' based on common descent and similar experiences" (2004:143) in which many found that they shared the same experiences such as going to church, growing up with extended family, living in similar houses in similar suburbs and an identity that was not their parents' and not like their local hosts. Media and entertainment such as music, plays and television provide avenues in which Pacific youth can positively express their identity. The Afro-American influence is notable in Aotearoa Pacific music. This is because Pacific music artists identify with the Afro-Americans and note the parallels with colour and hardship (Friesen, 2000). Nonetheless Aotearoa Pacific music is just that. Although the influences on the style and composition of music may come from abroad the themes and issues are Pacific (Bennett, 2002; Zemke-White, 2005). In King Kapisi's song 'Screams, from the old plantation', he talks about his Samoan culture and some of the issues relating to being Pacific in New Zealand such as the loss of language. One phrase from the song, 'second migration, we all paying homage to the old plantation', can be interpreted as referring to how Pacific people still acknowledge and revere Pacific homelands no matter where they have migrated.

Politics of identity play an integral part for younger Pacific generations. Their ideas and perceptions of health have been informed by both western science and cultural traditional perspectives. This situation has implications for their beliefs about health such as what constitutes a healthy being, the causality of illness and disease, and impacting on their health seeking behaviour. Their access to health remedies involves both western institutions such as health clinics as well as traditional healing. For most Pacific youth medical pluralism is a way of life involving movement between models

of traditional medicine and western medicine (Kinloch, 1985). Health concepts will be discussed more fully in the following chapter.

One major issue of identity contention facing second and third generations is being able to speak their mother tongue. For example Lee's (2004) study of Tongan transnationalism highlighted identity insecurities of overseas Tongans due to deficiencies in language and cultural skills. Park and Morris's (2004) indicate that there is variation of between 25 to 55 percent of New Zealand-born Samoans who are able to speak Samoan depending on age compared with over 80 per cent of those were born in Samoa. Despite this situation some New Zealand born Pacific peoples may not be able to speak their mother tongue but still have no qualms self-identifying themselves as a Pacific Islanders.

Over the past forty years since mass migration to New Zealand after World War 2, replication of Pacific homelands has taken form within Auckland's landscape in ways that have both ensured and recognised Pacific social integration and interaction with place (Macpherson, 2002). The notion of 'Pacifiness' is a creation of the emerging sense of place and location combined with politics of identity in a New Zealand context. Thus a recursive relationship has occurred with Pacific peoples in Auckland where in New Zealand and, more specifically, Auckland, new identity positions have emerged not out of cultural heritage but from location (Spoonley, Bedford & Macpherson, 2003) a process that echoes Eyle's (1985) sense of place concept discussed earlier.

2.5.3 Aucklands Pacific ethnoscape

Drawing on Appadurai's (1997) idea, an ethnoscape is a perspective on a place and society helping to define those ideas. Ethnoscaping aptly illustrate the recursive sense of place and identity. The three elements of ethnoscape are physical, transitory and metaphysical phenomena. There has been a debate over the politics of difference in terms of whether ethnic concentrations and ethnoscaping emphasize segregation or otherness or whether they create a dynamic sense of cultural identity (Friesen, 2000). The Auckland Pacific ethnoscape can be, and should be, regarded as reflecting the latter argument in which expressions of cultural identity are manifested. Further,

Friesen et al's (2005) study of the Auckland suburb of Sandringham found that the suburb that was once regarded as the epitome of the 'kiwi suburb' has evolved because of Indian transnationalism involving the movement of Indian migrants, goods and information.

The first element of an ethnoscape refers to tangible objects in the built environment. There is an undeniable Pacific influence in the landscape and architecture in Auckland especially in suburbs such as Otara and Mangere where the town centres in both suburbs have Pacific sculptures and motifs. The two most recent structures of prominence and importance that have been built in Auckland are the TelstraClear Pacific centre in Manukau City and the University of Auckland's *Fale* located at the city campus (see figures 2.4 and 2.5). The *fale* is the traditional architectural form of dwelling for Samoan and Tongan culture and in following this theme the University of Auckland's *fale* has been built in much of the same way with the roof is shaped similarly to the traditional thatched roof and the exterior designed so as to recreate the openness of a traditional *fale* using large glass panels. Over time the *fale* has become an icon that represents the Pacific in media discourse. The creation of the *fale* at the University of Auckland eventuated out of the increasing numbers of Pacific students and has become a symbol that reflects the increasing importance and influence of Pacific cultures for the University and Auckland in general. The fact that a large, powerful and renowned tertiary institution has included a symbol of Pacific art and culture in its landscape illustrates the recursive relationship of place and identity.

Figure 2.9: University of Auckland Fale Pasifika



Figure 2.10: TelstraClear Pacific Events Centre



Source: TelstraClear, 2006

The transitory component of Pacific ethnoscape includes such aspects as markets, festivals and events which is not a permanent feature of the landscape. Popular examples include the Otara Flea Market open every Saturday morning, the annual Pasifika Festival in Western Springs and the annual Auckland Secondary Schools Cultural Festival in Manukau City. Finally the metaphysical component refers to intangible elements such as language, public attitudes, fashion, literature, theatre, film and ethnic networks. A recent article ‘The rise of Pollywood’ in by Wong (2006), noted that a major cultural shift within New Zealand feature movies, has come out of Auckland which reflect Pacific identity. There is also a clear Pacific influence in regards to fashion especially with the popularity of Pacific motifs in tattooing. One of the more considerable metaphysical evidence is language. The Samoan language is actually the second most spoken language in New Zealand (Ministry of Pacific Island Affairs, 2002) and both national and local government agencies have recognized this significance of language barriers in such a migrant country by translating some of their publications into Pacific languages.

A Pacific ethnoscape in Auckland has been created by and for Pacific people, and has subsequently been endorsed and enhanced by the dominant culture(s) (for example, prominent iconic buildings and City Council sponsorship for festivals). Arguably, the

different components that make up this Pacific ethnoscape also serve as an identity markers for the individuals living in those communities (Vaoiva, 1999).

2.6 Conclusion

TB is a major concern within the Pacific although the incidence of the disease is not distributed evenly. Some of the TB rates in the Pacific, such as Tonga and Samoa, are higher than rates for Pacific populations in Auckland. The assertion that Pacific people's poor socio-economic status encourages the incidence of TB requires an understanding of the process of migration to establish why these migrants occupy the lower spectrum of society. Understanding the motives for why people migrate and their experience of place after settlement becomes an important element in discerning migration outcomes. The intersection of place and migrants played out within the Auckland landscape allows rich opportunity for interpreting sense of place. The fact that there is a Pacific ethnoscape in Auckland provides evidence for recursive ideas of place. Understanding Pacific people's identity is therefore imperative to understanding migrant's sense of place in their new homelands. For migrants in New Zealand, their change of location also impinges on their identity. For New Zealand-born Pacific people living in Auckland their identity is influenced by both western urban culture and Pacific traditional culture. Place therefore plays an active role in the construction of identity and this, in turn, influences peoples explanatory models, perceptions, practices and behaviour. Understanding the complex nature of place and identity is essential in understanding people's health beliefs.

Chapter 3

Soifua maloloina: Pacific health perspectives

“Health is everything – not just anything”

Tongan Proverb

3.1 Introduction

This chapter discusses western health perspectives and outlines two western models of health: the epidemiological transition and the health transition theory. This is then followed by an exploration of Pacific health perspectives to illustrate the difference between Pacific and western ideas of health and stressing the importance of identity on health frameworks. As there is no one generic Pacific health framework or paradigm as such the next section of the chapter provides an example by analysing a Samoan health framework. Parson (1985) provides an overview of health paradigms of the different south-west Pacific nations. In Samoa there is no standard health framework for Samoans as Samoan medicine is an open system. Thus, the Samoan health and medicine framework outlined is my own interpretation using Macpherson and Macpherson’s (1990) analysis of Samoan medical belief and practice as a guide. The openness of Pacific health perspectives facilitates an exploration into medical pluralist themes. This is examined by reviewing health perspectives of Pacific migrants.

Health is a social phenomenon and deeply embedded within culture. As such there is a relationship between health and other social processes. The second part of the chapter explores the health relationship with migration and social networks, two social processes that are of significant, and very important to Pacific peoples. In examining migration and social networks, tuberculosis will also be considered in these two contexts to explore how social processes can impact on disease ecology.

3.2 Western models of health

The World Health Organisation (WHO) proposes that health is a holistic, integrative and social phenomenon that it is best understood not just as the absence of disease but as a state of complete physical, mental and social well-being (Ministry of Health, 1997). Thus health as a framework includes both biomedical and social parameters. Despite this attempt to forge an encompassing framework the western perspective on health is intrinsically related to sickness and the physiological well being of individuals (Kinloch, 1985). Over the last 150 years health has undergone a gradual process of medicalisation whereby the nexus of health has been disease (Pollock and Finau, 1999). This is inextricably linked with the rise of biomedicine within the western health framework.

The biomedical paradigm is premised on western scientific and rationale ideologies and has led to the following four assumptions:

1. Disease is a deviation from the hypothetical standard for normal biological functioning.
2. Each disease is assumed to be mediated by a specific pathogenic agent.
3. Diseases are assumed to be generic in symptoms and locations.
4. Biomedical focus on curing rather than prevention (Pollock and Finau, 1999).

Western medicine has sought to improve international health standards by addressing these four assumptions. However, as the WHO definition of health implies, health is more than simply maintaining life by eradicating anomalies in the human biological system. What is needed is a socio-ecological approach to understanding health (Kearns, 1993).

Lifestyle, cultural attitudes and social values help to shape and structure a community's understanding of health. Western societies have held medical institutions and personnel in high esteem. This has led to very transparent notions that those within the health sector have been through vigorous specialised training and that medical institutions have strict codes and systems as well as being well-equipped technologically to deal with health issues and problems (Macpherson and

Macpherson, 1990). This situation reflects western society's expectations of professionalism and competency from the health sector. Explanatory models of disease and health in western thought are now being extended beyond the biological and biomedicine logic to the extent that models now take into consideration the social factors surrounding disease and health (Gesler and Kearns, 2002).

3.2.1 Epidemiological transition model

In 1971 Omran theorised an explanation for differing health, disease and mortality patterns across regions and countries over time to extend and explain the classical theory of demographic transition (Vigneron, 1993). This theory is known as the epidemiological transition and is best defined using Omran's (1971) own definition, that:

“The theory of epidemiological transition focuses on the complex change in patterns of health and disease and on the interactions between these patterns and their demographic, economic and sociologic determinants and consequences.” (Omran, 1971: p.161).

Omran devised three basic models of the epidemiological transition in which countries could be categorised. First, is the Classic (Western) model of epidemiological transition which is characterised by low fertility and mortality rates where societies have already undergone modernisation. Morbidity becomes the prime index of health instead of mortality as degenerative and chronic disease problems become prevalent whereas infectious and viral diseases are of little consequence.

Second, is the Accelerated epidemiological transition model. This model's major distinctive features are that societies reach low rates of mortality faster than Classic model societies and the shift to degenerative diseases is much faster and Omran cites Japan as a classic example of an Accelerated society. Third, is the Contemporary or Delayed model can be applied to most developing countries. The main characteristic of this model is a slow decline in mortality rates whilst still maintaining a high rate of fertility by western standards. Child and infant mortality rates still remain high and similarly rates of mortality caused by infectious disease remain high. Omran's (1971) model provides a basic foundation in which to examine health patterns of societies in a broader and more holistic context outside of the realm of modern medicine and

science. However, the model has its limitations and as such has been heavily critiqued.

Some authors have revised or extended this theory by including other models to make allowances for the role of individualistic behaviour and lifestyles as significant determinants of health patterns (Lewis and Rapaport, 1995; Trlin, 1994). The model does not make allowances for regional differences within nations where one part of a nation maybe at a different stage of the model than another part mainly due to social reasons such as socio-economic polarisation (Beaglehole and Bonita, 1997). Furthermore the model's dichotomous biomedical approach to illness as either infectious or non-infectious becomes problematic especially for Pacific and other traditional societies which have a more holistic approach to health and believe in illnesses caused by supernatural beings and deities (Whistler, 1992).

For Pacific societies the epidemiological transition applies but in a limited manner as it can only partially explain Pacific health patterns in Pacific (Foliaki and Pearce, 2003; Lewis and Rapaport, 1995). This limitation occurs because, although after first contact with Europeans there was high fertility and the major cause of mortality was due to infectious diseases, the present health situation of Pacific societies does not exactly follow Omran's contemporary or delayed model. While there is currently a rise in lifestyle diseases within Pacific societies infectious diseases are also still high especially with the resurgence of some infectious diseases such as tuberculosis. Further, Pacific fertility rates have not yet decreased to a great extent. For those reasons, Omran's epidemiological transition theory can not be strictly applied to Pacific societies. Butt (2002) suggests that a more appropriate and applicable theory for Pacific's health situation is Caldwell's (1993) health transition.

3.2.2 Health transition theory

According to Caldwell (1993) health transition is when biomedicine becomes progressively more influential and pervades social and cultural realms, accompanied by individualistic behavioural changes. Positive behavioural changes results in better health over a longer lifespan. The transition varies with the degree of exposure and access to biomedical systems as well as according to cultural factors such as

education, values and attitudes about life and death (Caldwell, 1993). In essence, the transition explains and describes the change from high fertility and mortality from mostly infectious diseases in third world countries or traditional societies to low fertility and low mortality from mostly non-communicable diseases in modern societies by drawing on cultural, behavioural and structural factors (Butt, 2002; Finau et al, 2002). Like the epidemiological transition theory this theory also fails to recognise other illnesses apart from infectious and non-infectious disease as well ignoring the interaction between the two disease types (Beaglehole & Bonita, 1997).

Caldwell's health transition is better suited to analysing the health patterns of Pacific societies than the epidemiological transition because it examines not only societal factors but also behavioural and structural factors. Consequently, it allows for the examination of structural, institutional and political changes together with Pacific indigenous epistemology to gain a better and more objective understanding of the health transitions in Pacific societies. Conversely, to gain an even better understanding of the health transition in Pacific it is necessary to look beyond structural, social and cultural factors of Pacific societies to the changes that have moulded these factors to what they are at the present. This is because, like other countries with colonial pasts, Pacific societies have undergone enormous changes since European contact (Foliaki and Pearce, 2003).

To fully examine and analyse the health transition for Pacific nations it is necessary to consider other transitions that have occurred within the Pacific as the changes in health of Pacific peoples have not occurred within a vacuum independent of other factors. Changes in Pacific people's health are, in fact, only one of many interdependent transitions where fundamental changes in the lives of Pacific peoples are affected by, as well as, affecting each other. The health transition model also needs to take into account the economic, political, environmental and social transitions that have taken place within Pacific societies at the same time. Furthermore, the model is only capable to describing the past and fails to provide some predictive future prospects of the health of societies (Beaglehole & Bonita, 1997).

3.3 Pacific health perspectives

The epidemiological and health transition theories and their implications may be a poor fit within some Pacific contexts. This is because of the different health perspectives that Pacific peoples hold, especially for those still living in their homelands. What constitutes illness and sickness for Pacific peoples may differ to the Western notions of the same constructs. It is difficult to construct a generic Pacific health paradigm as such, due to the diversity of cultures that the term “Pacific” encompasses. Despite this diversity there are two common health fundamentals that have been well documented that Pacific peoples share: a holistic notion of health, and health as a family affair rather than an individual matter.

Firstly, there is an emphasis on the holistic notion of health in which being healthy is determined by a person’s total well being, that is, not only their physical well being but also their social, environmental and spiritual well being (Bathgate, 1994). Therefore the causation of illness includes not only natural causes but also supernatural sources and tensions in relationships with other people and aspects of the environment (Whistler, 1992; Chambers and Chambers, 1985; Parsons, 1985). In ancient Pacific most illness was attributed to supernatural origins or *aitu* but in recent times the number of illnesses attributed to deities and supernatural agents has reduced significantly (Whistler, 1992; Macpherson and Macpherson, 1990) but is still regarded as a valid cause.

Illnesses caused by deities are often believed to be the consequence of transgressions on *tapu* (Finau, 1980). *Tapu* in this vein pertains to the rules of social behaviour toward sacred matter. Furthermore, illness may not only afflict the person responsible for the transgression but may also afflict other family members (Whistler, 1992). Tensions and stresses on social relationships between individuals can also cause illness (Baddeley, 1985; Parsons, 1985; Macpherson and Macpherson, 1990). Therefore in order to keep healthy and to sustain wellness one must also maintain harmony with fellow family members and villagers. Thus, a Pacific perspective on health encompasses not only a widely varying range of factors for well being but also causation of illness.

The second fundamental premise is the notion that individual well being is a collective concern and so becomes a family affair (Laing and Mitaera, 1994; Tukuitonga, 1990). Consequently, this belief impacts on a Pacific person's health-seeking behaviour. The decision about who to consult is not made at the individual level but becomes a family affair involving not only the nuclear family but also the extended family (Baddeley, 1985; Laing and Mitaera, 1994). A personal reflection can assist this recognition:

I have experienced and encountered this collective concern many times in the past when I have been ill that I have consulted with traditional healers that have been recommended and sought after by not only my parents but also by my aunts, uncles, church members and close family friends. Therefore, it was not unusual for a whole community to know if I was sick and why at any given time and strangely enough for me this is normal.

3.4 Samoan medical framework

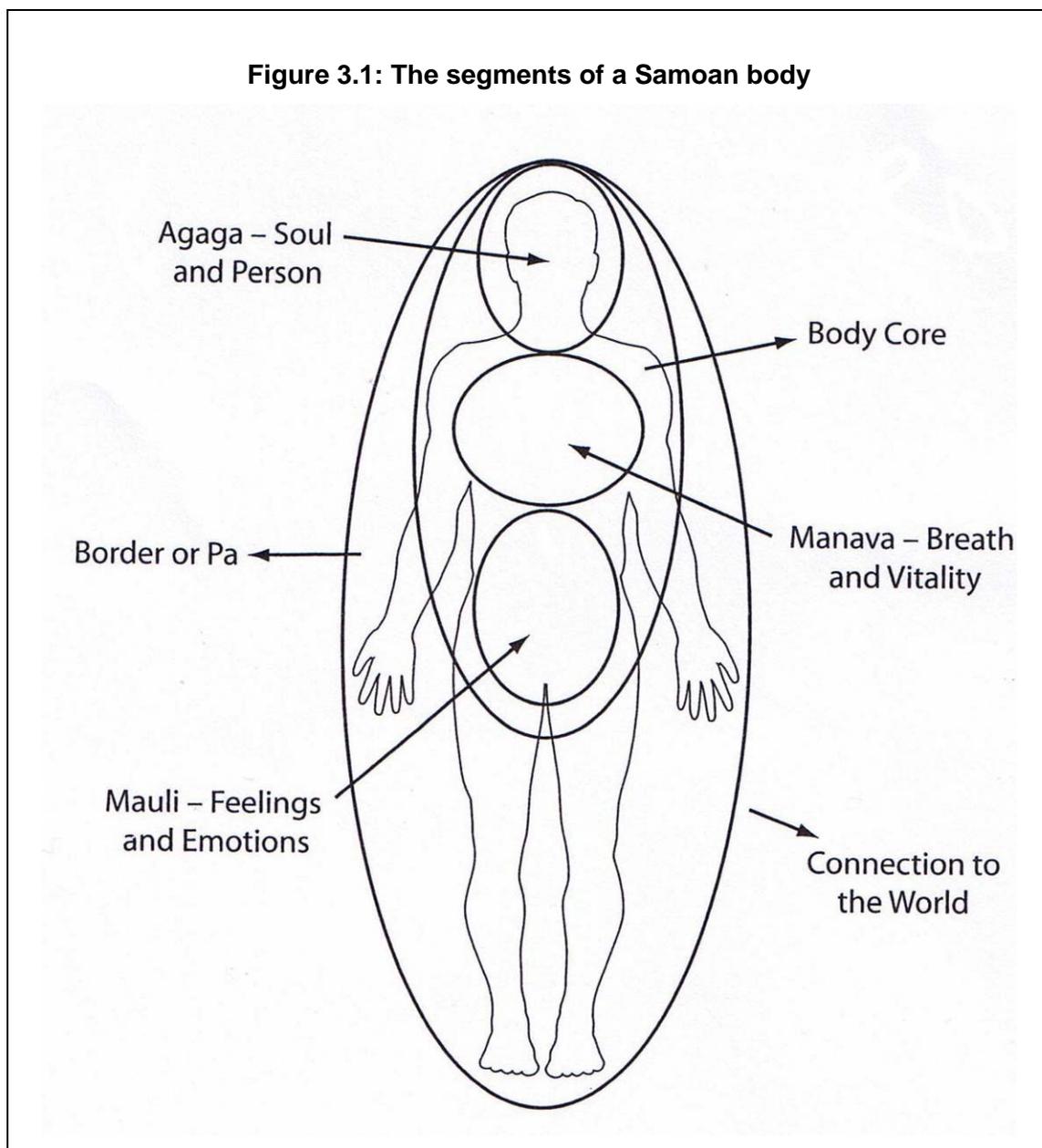
The Samoan concept of health is termed *soifua maloloina*. *Soifua* means 'to live' or 'life' while *maloloina* means a rest, or to recover from sickness, or health (Laing & Mitaera, 1994). Illness when translated into Samoan is *ma'i*. The term *ma'i* is a oral socially constructed term by Samoans used to encompass a plethora of explanations for ill health that are not often considered by western thought (Drozdow-St Christian, 2002). Health is integral to the Samoans' worldview and plays a major part in cultural practices and social behaviours. However, there is no one particular Samoan worldview on health as there are regional variations in health beliefs and practice. Therefore Samoan medicine is an open system. As such, it is difficult to construct a generic Samoan health paradigm and thus there is no one traditional medical system ((Macpherson & Macpherson, 1990). The Samoan medical framework outlined here is a general system based on and informed by Macpherson and Macpherson's (1990) publication *Samoan Medical Belief and Practice* among others. This Samoan medical framework is a system of three parts; illness and health beliefs, diagnosis and intervention.

3.4.1 Illness and Health belief

There are two sets of belief on health and illness and each is a loosely integrated model.

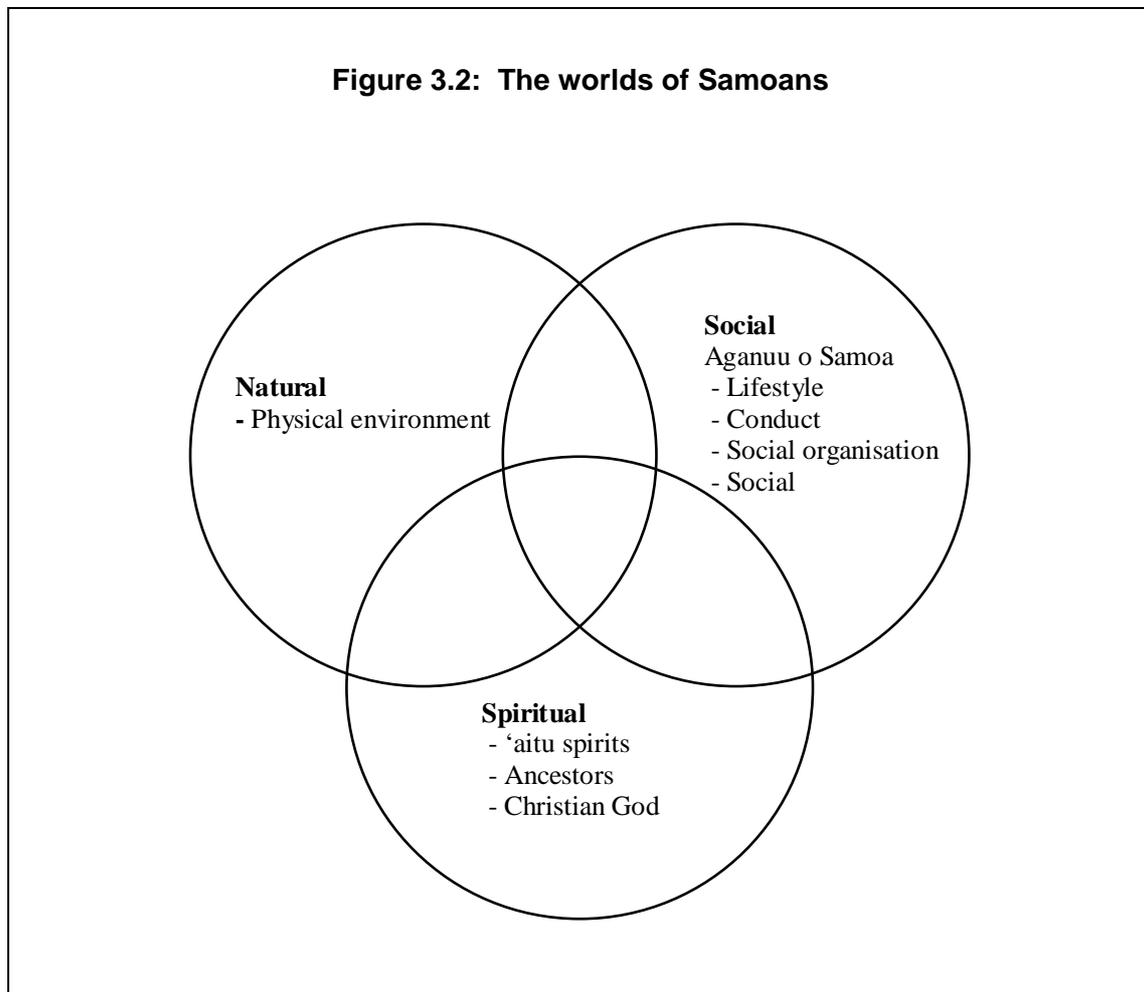
1. Samoans and the three realms

Bodies in Samoa are divided into three segments: the interior which is also divided into three parts (*agaga*, *manava* and *mauli*), the boundary (exterior) and things outside. These segments are all interdependent and are indivisible as shown by the diagram below (Drozdow-St Christian, 2002).



Source: Drozdow-St Christian, 2002 p. 164

The third segment of the body refers to 'worlds' where in Samoan culture Samoans live within three realms or worlds:



- Natural world - The natural world is the physical environment in which Samoans live. The environment plays an important part in a persons well being and therefore a person must adapt to the physical conditions of the environment.
- Social World – This world pertains to the lifestyle and conduct of a Samoan where a Samoan is living by Samoan customs, *o le aganu'u o Samoa*. This world also relates to social organisation and relationships between individuals and the community which includes family, extended family, church community and so forth (Balkenhol, 2004). From a young age children are taught their role through their life course so that rights and obligations are clearly understood.

- Spiritual World – This world relates to spirits or *aitu*, ancestors and the Christian God.

The Samoan condition and embodiment is influenced by the person's relations with and between these three worlds. Although Samoans acknowledge that ill-health and sickness is inevitable (Kinloch, 1985) the desired state of the Samoan is *soifua maloloina* or a state of well being where the three worlds are stable at equilibrium. Thus, illness occurs if a Samoan's relationship with one of the worlds becomes unbalanced and close family members may also become ill as a result. Samoan custom has also taken on particular Christian values as traditional custom. As a result same sex relationships are seen as *sa* or forbidden. Therefore children who openly engage in same sex relationships invariably cause considerable stress in parents. This in turn can manifest in to severe illness. The text box below illustrates Drozdow-St Chrisitan's (2002) argument that illness is often about loss of dignity. These beliefs explain the existence of illness, the causation of illness and the bases for intervention.

In one Samoan family a daughter was caught having a lesbian affair. On s learning about this, the father suffered a severe stroke and the family attributed this to the stress the family had caused. Because of the deep embarrassment and in order to protect the family name no one outside the immediate family knew the cause of the father's stroke.

The above story shows how a Samoan social transgression caused an illness. This social transgression therefore upset the father's *agaga* or soul. The transgression upset his *agaga* and he had a stroke which is a neurological condition. Therefore there is a relationship between the type of illness and social causality of illness.

2. Body's normal function

There is a set of beliefs which explains the body's normal function and the nature and causes of illness from particular malfunction. This is more in line with the western biomedical system in which this set of beliefs is related specifically to the human anatomy. However, in keeping with the notion of equilibrium in this anatomical sense one important facet of a Samoan's body is the *to'ala*. The *to'ala* is a nebulous life essence (Forsyth, 1983; Heath, 1973; Macpherson and Macpherson, 1990; Whistler, 1992). This mobile and pulsating phenomenon resides in the abdomen near the solar

plexus. If the *to'ala* moves out of place then this can cause a range of illnesses and a feeling of unwellness. Conversely, as long as the *to'ala* remains in place a person's physical state remains in balance. To illustrate:

I had the unfortunate experience whereby my to'ala was moving out of place causing me great distress with headaches and migraines. Of course at the time I didn't know that my to'ala had moved, let alone know it existed at all. After three days of taking migraine medication a family friend introduced me to a fofo or traditional healer who, she swore, could cure me. The fofo began to lift up my shirt baring my navel which at the time I thought quite odd so I lay there quietly thinking "I have a sore head not a sore stomach". However, as soon as she started massaging I looked down and there I saw a pulsating ball about the size of a small apricot moving towards my chest. It was a bizarre and out of body experience. As soon as I walked out her door I felt absolutely fine, although, still a little bewildered..

3.4.2. Diagnosis

A standard detailed diagnostic model is difficult to outline. Samoans have a basic understanding of health and the anatomy. Often, when Samoans feel the onset of illness, they will determine with the help of family members whether they have *ma'i samoa*, Samoan illness or *ma'i palagi*, *Palagi*⁶ illness.

Ma'i Samoa

Ma'i samoa or Samoan illnesses are those illnesses which Samoans believe are indigenous and which therefore have a Samoan remedy. There are only a few illnesses classified in this category for historical reasons. Little is known about illness and health before contact with Europeans. However historical accounts from missionaries such as Williams and Pratt and explorers such as Turner, Wilkes and Roggevein confirm Samoans own account that there was little illness in pre-contact Samoa with the exception of higher child mortality (Forsyth, 1983; Macpherson, 1985; Whistler, 1992). Because of the islands' isolation, Samoans enjoyed stability in epidemiology where most illnesses arose from exposure to the elements and from supernatural beings. Thus most illnesses were due to the heat from the sun and from rapid cooling caused by cool breezes. Samoan customs and daily rituals were organised to take into account climatic conditions so as to avoid illness and imbalance. For example all

⁶ Samoan term for European

activities were organised into two periods; the first period beginning at sunrise and the second period beginning in late afternoon, in order to avoid exposure during the time that the heat of the sun is most potent (Macpherson and Macpherson, 1990).

Ma'i aitu or supernatural illnesses are also considered *ma'i samoa* and are those illnesses which Samoans believe are caused by spirits or ghosts. There are two types of *ma'i aitu*. The first illness is possession whereby an individual is possessed by a spirit. The second type is a related ailment in which a spirit does not possess an individual but rather inflicts illnesses and ailments on an individual as retribution for transgressions.

Ma'i palagi

These illnesses are the result of contact with *Palagi* and include communicable diseases as well as non-communicable diseases (Foliaki and Pearce, 2003; Lewis and Rapaport, 1995). Specific illnesses can be distinguished and the names of these are Samoan cognates of the English names, for example *misela* (measles) and *taifoi* (typhoid). The incidence of these illnesses can be related back to the health transition. There are some instances in which some people regard what others call *ma'i palagi*, as *ma'i samoa*.

Lifestyle disease such as diabetes, cardiovascular disease and hypertension are increasingly important among Samoans as well as in Pacific people in general (Lewis and Rapaport, 1995). As with communicable diseases, Samoan medicine is ineffective in treating these diseases. This situation however, does not undermine the legitimacy of Samoan traditional healing but further stresses the importance of Samoa's model of wellness and health.

Modernisation and development of Samoa as well as other island nations has led to the introduction of undesirable foodstuffs such as high calorie soft drinks and high cholesterol processed foods and fatty meats (Foliaki and Pearce, 2003). This change has caused a shift in the balance of Samoans' diet and nutrition leading to detrimental effects. Coupled with this is the sedentary lifestyle most Samoans have adopted with the advent of mechanisation and technology replacing the need for physical and manual labour (Lewis and Rapaport, 1995). This, however, also represents a deviation

from traditional social custom in which physical labour and an active lifestyle were an integral part. The introduction of *Palagi* phenomena has led to an imbalance in the traditional Samoan framework causing serious health problems for Samoans. Drozdow-St Christian (2002) also argues that although *ma'i palagi* are blameless, the onset of illness can be linked back to some element of social disrepute or despair.

3.4.3 *Traditional healers*

If self-diagnosis proves difficult, which is often the case, the individual or family will seek the help and advice of traditional healers. Like Western society there is specialisation and distinction amongst the healers. Firstly there is the *fofō* and *taulasea* who specialise in massage and *ma'i samoa*. Then, there is the *fogau* who are in essence bonesetters and finally the *taulaaitu* who can be referred to as exorcists (Forsyth, 1983; Heath, 1973). Within these four categories healers often specialise in a group of illnesses. This specialisation may occur for one of three reasons. Firstly, specialisation may occur through training where the healer was only trained in dealing with certain illnesses. Secondly, through experience and expertise, a healer may become more proficient in one area of healing. Thirdly specialisation can occur due to varying degrees of success (Macpherson and Macpherson, 1990). So if a healer has been able to successfully treat a certain group of illnesses the healer will decide that God has granted them the gift to heal only that group of illnesses in which they have had successfully treated.

Traditional healers for the most part live normal everyday lives in which traditional healing is not so much a career but a facet of their daily lives. Within individual villages it is difficult for a stranger to locate a healer as there is no 'healing' facility as such. Instead a healer often conducts their services either at their residence or at the residence of the patient. Healers gain their status by way of two avenues: either by inheritance, or by the calling of God (Macpherson, 1985; Kinloch, 1985). It is Samoan belief that the wisdom and success of healing is bestowed upon healers by God and is evidence of a good relationship between God and the healer (Macpherson and Macpherson, 1990; Whistler, 1992). In this way many healers believe that the prestige from being chosen to do God's work and fulfil his purpose is more important than secular recognition. Thus healers tend to refuse any reimbursement for their

services. The concept of fees and payment for services rendered is incomprehensible to healers as they believe that by accepting payments they may lose their God-given talent (Kinloch, 1985). However in accordance with appropriated Samoan customs, a gift or *meaalofa* is often provided to the healer as a token of the sick person's appreciation to the healer. The work of healers does not produce material wealth but this does not deter healers from practising as they believe that their true and just reward will come in the afterlife (Macpherson, 1985).

Traditional healers recognise and understand their range of capabilities as well as their limitations. This is important as healers will never mislead their patients and so, if they can not treat a patient, they will refer them to another healer who can help (Kinloch, 1985). The social network of healers becomes a vital component of health practices within the Samoan paradigm as healers will have extensive knowledge of other healers and their field of their expertise. In the same way healers will also refer patients who they have diagnosed with *ma'i palagi* to European doctors and hospitals (Macpherson and Macpherson, 1990). Thus healers recognise that there is a duality of health systems in the framework which they occupy.

The diagnostic procedure and its elements relate to the particular view of relationships and equilibrium between the individual and their natural, social and spiritual worlds. A procedure is carried out to determine what those causes are and the relevant treatment in any given condition, through examination of the body and a line of questioning. A healer's diagnosis is only confirmed if treatment is successful. Beyond this generalisation the diagnostic model is very individual-specific and is based on the healer's own beliefs and perceptions, their level of skill and expertise as well as training.

3.4.4. Intervention or treatment

Treatment of *ma'i samoa* by *fofo* can be categorised as either contact or non-contact treatment. Contact treatment is either through massage or *milimili* by using coconut oil, *ti* leaves or other herbal remedies or the consumption of herbal medicine. Contact treatment is usually used for illness arising from the imbalance of the natural world.

Non-contact treatment is used for *ma'i aitu* and illnesses in relation to the social world. Fasting or *anapogi*, or *faalaina* is often used when it is believed that the individual has transgressed against God. This is also known as *agasala*. If it is believed that a person has been possessed (by *aitu*) then the *taulaaitu* will perform incantations in order to relieve and heal the patient. Therapy, advice and counselling are given to those with illnesses related to the social world. Because of the high status and respect that the healer or *fofo* command, the advice given is generally, always carried out. Also patients may fear that greater consequences may befall them if they do not heed the advice.

Because of the social stigma attached to illness in Samoa, some families may try to hide or deny illness and may try to treat the symptoms themselves. If this remedy fails then Samoans may seek western medical attention as an alternative. Western health professionals offer a greater level of greater privacy where examination, diagnosis and treatment are normally conducted in private rooms away from public view. Preservation of a family's reputation is the main reason for avoiding traditional healers even if it is known that their treatment can rectify their problem (Drozdow-St Christian, 2002).

There are no set rules about the application of this Samoan medical framework for those who live outside of Samoa and who were not raised in Samoa. Because of Samoan migrant and transnational histories those to whom this framework applies becomes somewhat complicated and often more a matter of choice. However, in cities with large Samoan migrant groups such as Auckland, Sydney and Los Angeles which have long-established Samoan communities, most of the ideas and beliefs embodied within this framework exist and this is evident with the existence of *fofo* in these cities. Furthermore, New Zealand-born Samoans like me may also become afflicted with *ma'i samoa* in New Zealand. However, a larger number of overseas-born Samoans who have not been grounded in a traditional Samoan upbringing and do not identify themselves as Samoans, may feel that this framework is not relevant for them and therefore has no practical use or value to them. Nonetheless, overseas-born Samoans and foreigners who visit Samoa and have no knowledge of the Samoan medical framework may become afflicted with *ma'i samoa* while in Samoa, as is well documented by Macpherson and Macpherson (1990).

3.4.5 *Dual systems*

The Samoan health paradigm recognises that there are two separate but complementary systems in place: Western medicine and traditional healing. Rather than viewing western medicine as a competing model the Samoan health paradigm has embraced Western medicine and science and acknowledges the value, role and place that it has within Samoan societies. Samoan traditional healers point out that Samoan medicines and remedies are ineffective in treating European illnesses while at the same time, Western medicine cannot successfully treat Samoan illnesses because it does not understand the intricate causal relationship between Samoan illness and the three environments which Samoans live in (Macpherson, 1985). Thus, distinguishing illness becomes crucial for patients and healers.

Macpherson (1985) argues that there will always be a need for traditional medicine as there will always be *ma'i samoa*. Furthermore, the traditional health paradigm is traditional only because it is used and implemented by those people deemed to be as traditional healers. Both systems fulfil and meet the different needs of contemporary Samoan society. As such they are both integral to Samoan health practices and understandings. Samoans do not consider the two systems as mutually exclusive; rather, they view them as complementary systems that are to be used to achieve the same goal and purpose (Kinloch, 1985).

3.5 Traditional health perspectives in Auckland

Pacific people living in Auckland still utilise traditional medicine and easily move between the two systems of health (Tukuitonga, 1990). Subsequently, ethnicity and ethnic cultural beliefs in health have a place in New Zealand. And while it has taken sometime for authority to accept Pacific traditional medicine as part of health services for the Pacific people the Government has finally recognised this reality. Despite migration the cultural logic of some Pacific people still impinges on every aspect of their lives including health (Bassett & Holt, 2002). Therefore, health-seeking behaviour is still influenced by Pacific cultural ideas, beliefs and social structures (Tukuitonga, 1990). For example when a person in a Samoan family becomes ill the family tries to diagnose the patient themselves to distinguish whether it is a Samoan or a Western illness in order to determine which health practice they will take. This is

even true for some first generation New Zealand born Samoans whose parents have instilled in their children at an early age, Samoan customs and cultural beliefs in their children representing a diffusion of indigenous cultural ideas (Kinloch, 1985).

Arguably there are intergenerational differences in terms of Samoans people's attitudes and practices around health and health-seeking behaviours. Some migrant parents still staunchly hold on to their traditional health beliefs their children may not necessarily espouse such value. Those who still use traditional practices do so to supplement western practices. This is evident in Abel et al's (1999) study of infant care practices of the major Pacific groups in Auckland. Traditional and customary practices were used to enhance both mother and baby's well being and customary practices were commonly used for the spiritual well being of the baby.

So far I have demonstrated that there is a recursive sense of place between Pacific peoples and the Auckland landscape. Pacific peoples bring with them healing methods and healers when migrating and for Auckland this has meant a new landscape of healthcare for Pacific people's that reflects a medical pluralism. Although people migrate in order to seek better opportunities in employment and education, the decision to migrate may have negative consequences on people's health. I discuss the relationship between health and migration next.

3.6 Health and migration

The relationship between health and migration has been well recognised with migrant studies often focussing on the health outcomes for migrants in their new homelands (Kasl and Berkham, 1983; Elliott and Gillie, 1998; Acevedo-Garcia, 2000). However, more study and analysis is needed to clarify the relationship between the two, to establish how migration impacts upon, and is affected by health (Gatrell, 2002). There is a discernable gap in the literature given that the core area of research is focused on transnational migrants who move from place to place. The determinants of health for transnationals will be different to permanent migrants. As Elliott and Gillie (1998) have noted, a shift in focus to the dynamics of the social and personal forces that influence changes in health in a migration context is needed. This requires taking a health perspective in migration which treats migration not as a single event,

but as a dynamic social process. In fact the event itself is not the main focus but rather, more importantly describing the individuals experience and relationship with other networks of people and institutions (Evans, 1987).

Some authors (Laing and Mitaera, 1994) have noted that the choice by some Pacific people to migrate for economic benefit and opportunity is made with the knowledge that New Zealand is one of the sources of ill health in the family. The impact of migration is not taken lightly by Pacific people as they acknowledge and are aware of both the positive and adverse affects that migration will have on families and health, as discussed in Chapter 2.

The association of ill health and migration is informed by the holistic health perspective. According to the Samoan health paradigm where moving to a new environment causes an imbalance in a family's well being and therefore ill health is inevitable (Macpherson and Macpherson, 1990). The consciousness that ill health is expected once the decision to migrate is made provides an interesting development in the link between health and migration where, arguably, the mental and emotional well being of an individual and family has already been jeopardised even before the migration process has begun. However, some Pacific peoples migrate to New Zealand because of constant and persistent serious health problems. Further, because of the limited specialised services available in the Pacific for illnesses such as cancer and heart disease, migration for medical and health reasons is often the only viable solution to seek specialised health care.

However, urbanisation is increasingly attributed to the rise of non-communicable disease such as cancer and heart disease in Pacific peoples (Lewis and Rapaport, 1995). The rise in non-communicable disease in urban migrant cities stem from a lack of tradition in urban culture. In island homelands physical activity is a daily and common affair with traditional practices such as subsistence agriculture require hard manual labour. Further, the change in setting has meant a change in diet where western fast food and processed meals has commonly replaced the traditional menu. Fast food and processed food is far cheaper than traditional foods available in migrant cities as well as being more convenient with the change in pace of lifestyle (Finau et al, 2002).

Most health studies concerning Pacific peoples in New Zealand have been in relation to the socio-economic determinants of health once migrants have already settled in New Zealand. One exception is the longitudinal Tokelau migration study conducted by Prior and others in the 1970s. The study provided empirical evidence to show that migration does indeed impact health in a negative manner (Kasl and Berkman, 1983; Gatrell, 2002). Recent authors in migrant studies such as de Haan (1999) and Spoonley et al (2003) have illustrated the economic and political fragility of migrant communities since the 1990s mainly due, in part, to capitalism, globalisation and the changing world economy.

Urban centres to which Pacific migrants have migrated have undergone a significant employment change where cities have become service-based economies. This situation has created a mismatch between location and skills of many Pacific peoples (Spoonley et al, 2003). These circumstances have created problems in terms of employment and income and in many cases Pacific peoples utilise their transnational social networks for better economic opportunities. Consequently, this has had an effect on an individual and family's well being especially if a migrant family is frequently uprooted. The migration experience is further strained as migrants are blamed for transporting disease into their new homelands.

3.6.1 Migrants and TB

TB continues to be associated with migration where dominant ethnic groups in host countries view TB as an exotic disease from developing countries (Gatrell, 2002). Migrants from developing countries are often cited as the cause for the rise of TB in urban western cities especially by administrators who are against immigration (Gatrell, 2002). Currently, there is significant debate over the consequence of human migration for the spread of disease. Research suggests that immigrants who were infected with TB abroad are not the primary cause for the spread of TB to members of host societies. The migration process itself is of arguably less significance for precipitating TB disease than the living conditions encountered in the host country (Curtis, 2004). As I have previously outlined in Chapter 2, overcrowding and poor housing quality can induce the spread and transmission of infectious disease.

However, there have been studies which question the significance of poverty alone in TB disease (Curtis, 2004). The recent study by Davidow et al (2003) showed that although poverty was strongly associated with European populations with TB in New Jersey, no such relationship existed for the Asian populations. In this study it was shown that the rate of TB for young Asians was the same for those living in deprived areas and those living in more affluent suburbs. The implication is that social networks are important avenues for the distribution of TB.

In New Zealand the evidence shows that the majority of migrants or cases of those born overseas who developed tuberculosis disease, had been living in New Zealand for more than five years. This demonstrates that most of the migrants were most likely to be infected in New Zealand rather than in their country of origin (Carr et al, 2001). The table below shows the relationship between TB notification and length of time in the country for migrants.

Table 3.1: Time between arrival in New Zealand and Notification of tuberculosis for cases born overseas, 1995-1999.

Time from arrival in NZ to reporting	1995-99 Number	Percentage ⁷
Less than one year	164	20.9
One to five years	272	34.6
More than five years	439	44.5
Total	785	

Source: Carr et al, 2001

3.7 Social networks and health

Social networks refer to the social contacts of an individual such as kin, neighbours and friends. The individual is usually tied socially by shared values, attitudes and aspirations. Such networks maybe spatially concentrated. Contact can be described in terms of the number of contacts and frequency of contacts (Johnston, 2000; Smith, 1980; Stansfeld, 1999). The quality of support from social networks is an important variable in analysing an individual's social network. In general there are three types

⁷ Proportion of the total number of overseas born cases which were notified during that period.

of support; emotional, practical and instrumental support (Stansfeld, 1999). Social networks provide avenues for the dissemination of various phenomena through populations such as information and infection (Klov Dahl et al, 2001). The impact that social networks have on health is a double edged sword. Social networks can provide support in times of ill health and can also bring ill health by providing pathways to distribute infectious disease, such as TB.

Stansfeld (1999) suggests that positive effects of support, and isolation causing lack of support, has direct effects on people's health. Social support can also act as a 'buffer' to moderate the impact of acute and chronic illness. The argument suggests that the causal impact of the development of illness can be moderated by protective factors such as social support. Social networks can provide this support for individuals to reassure and comfort the individual. Social networks are also beneficial for those who have to adjust to, or cope with, the stress of a chronic illness. This was recently demonstrated in a study conducted by Veenstra et al (2005) where they studied the social networks of a neighbourhood in Hamilton, Canada. They concluded that there is a positive relationship between social networks and well being where networks were used as coping mechanisms to limit emotional distress in the face of health crises. Social networks, therefore, provide support on many levels such as practical support in providing transport as well as providing emotional support to boost morale during health scares.

Social networks for Pacific peoples are wide-ranging where the networks are based along kin, friends and church. Levy-Storms and Wallace's (2003) study into the social networks of Samoan women in Los Angeles found that the women have a high dependency on their extended kinship networks. Further, the churches are of similar importance as they facilitate cultural networks. The study found that these networks help Samoan women in coping and adapting to their new environment as well as providing channels to disseminate information on health and healing. Similarly, a study on Chinese women in Canada came to the same conclusions whereby Chinese women use their social networks in seeking health care from both traditional Chinese healers and Chinese specific medical care (Gatrell, 2002).

3.7.1 Outbreaks and social networks

As well as facilitating health seeking behaviour, social networks can lead to the unfortunate event of infectious disease outbreaks. Outbreaks have been associated with social networks and places linking infected people with source cases, hence the term, outbreak networks (Klov Dahl et al, 2001). An outbreak network is only linked with the connection to infectious disease, and this network may include persons, places and other objects that actively transmit infectious disease. As mentioned earlier, a serious TB outbreak in 1999 at a Pacific Auckland church group resulted in 27 notifications of TB as part of the outbreak (Carr et al, 2001). Outbreaks of TB among social networks are a major concern to Pacific peoples in Auckland especially with family gatherings and social events as well as demands for church activities on a weekly basis where contacts are continually made on a weekly basis.

3.8 Conclusion

This chapter has reviewed how identity influences health by reviewing Western and Pacific health frameworks. The differences in causality of illness and disease, the diagnosis process and subsequent treatment, illustrates how culture and identity influences health explanatory models. From a Pacific perspective, the openness of health frameworks facilitates an examination into medical pluralism for Pacific migrants. The practice of medical pluralism is more complex for New Zealand-born Pacific peoples, especially for those who do not identify strongly with Pacific cultures. The argument that migration impacts negatively on health has been examined by exploring the disease ecology of TB. Migration can facilitate the distribution of TB through poor housing and over crowding and through social networks. When reviewing this chapter in conjunction with Chapter 2, it illustrated that migrants do not necessarily bring active TB but rather that the outcomes of the migration process can initiate the progression of TB disease. As such, the lived experience of illness for Pacific migrants is embedded in immigrant realities and is informed by both western and Pacific health perspectives.

Chapter 4

Approach and method: The research process

*“To study the phenomena of disease without books
is to sail an uncharted sea, while to study books without patients
is not to go to sea at all”*

Sir William Osler

4.1 Introduction

As the title indicates, this chapter outlines my approach to the research and the methods used to achieve the aims of the study. First I discuss my positionality as a Pacific researcher and explain some of the personal issues surrounding my identity that arose as a result of conducting this research. The next section of the chapter explains the qualitative and quantitative approaches that I used for this thesis. This includes an important summary of the Health Research Council of New Zealand (HRC) guidelines for conducting health research on Pacific peoples, which informed and influenced the manner in which I conducted this research. I then outline my fieldwork in Samoa and Auckland and highlight some of the issues and difficulties encountered in the course of the research. Finally, the chapter concludes with an introduction to the participants in this study.

4.2 The right Samoan?

When I agreed to research the experiences of Pacific peoples with TB in Auckland I realised that I would have to face a number of challenges, issues and obstacles as a Pacific researcher. When I started this project I did not realise how stigmatised TB is, especially amongst Pacific communities. One of the challenges that I knew I may face was people’s bias and how other Pacific people would react to a study of this topic. Further, I wondered how other Samoans would feel about me interviewing them. Because the Samoan community in Auckland is relatively large, chances are that several people may be acquainted and know each other. I also anticipated that some

Samoa people may be reluctant to talk to me if they felt that they might know someone who I know or worse still, some may know me personally. Further, as I became to realise just how stigmatise TB is in Samoa, I was concerned that people may not want to participate in my research.

I was also wary of how this research would affect me personally and that it could impact on my own identity as a young New Zealand-born Samoan woman. At first, I contemplated the possibility that when I go to interview people in Samoa, that they might not view me as real Samoan because not only was I doing research based in an institution outside of Samoa but also because of my appearance with fair skin. Overseas-born Samoans face criticism from some people living in Samoa about lack of knowledge about *fa'asamoa* and especially about their inability to speak the Samoan language. These criticisms can at times be quite unwarranted and unfair to overseas born Samoans like myself who although have lived overseas, I have managed to retain my native tongue as well as understanding and still living by *fa'asamoa*, the Samoan way. For some, these criticisms are taken personally. For some people, the criticisms are considered as an attack on people's identity, especially when our interlocutors do not understand the complexities that overseas born Samoans face when trying to retain their culture as much as possible in a western society.

If doing research with Samoans in Auckland can be difficult, conducting research in Samoa is even more complicated. And when the research topic conjures up images of poverty, sickness and shame because of the stigma attached to TB, I knew I would be confronted with some resistance as some people can be reluctant to talk openly about their experiences with traditional healer and traditional beliefs and especially TB. While reviewing the literature for the project, I found that TB was a highly stigmatised disease in many societies, and anecdotes from my own networks indicated that many Samoans view TB as a poverty-related disease. As a young Samoan student researcher, fluent in written and oral Samoan, I wondered whether potential participants would understand, and could be persuaded that if they wanted the interviews conducted in Samoan, that it was possible to do so. I was mindful of the researcher as an 'insider' or 'outside' debate, and wanted to assure people that I was indeed, a young Samoan researcher fluent in Samoan who was prepared to work with

participants to document meaningful information about Pacific people's health and TB, through my research.

Smith (1999) argues that, in indigenous research a researcher can be an insider and an outsider in multiple ways (cited in Williams, 2004). As I have alluded to above, I found myself being an 'insider' in different ways depending on who I was interviewing. My 'insider' status was often a combination of being young, a New Zealand-born Pacific person and being female. However, as will be illustrated further in the course of this discussion, being born into an ethnic group does not ensure insider status within it. When interviewing Pacific peoples who were not Samoan I was both an outsider and insider because of shared common Pacific values such as respect, reciprocity and collective responsibility (Williams, 2004). To some extent I was an insider but because I am not from that ethnic group and do not fully understand all the cultural norms and protocols I was also an outsider. So, as a Samoan researching issues of concern to other Pacific peoples, it is important that my research reflects a Pacific world, as well as including indigenous ways of knowing (Nabobo-Baba, 2004). More importantly, my research sought to gain knowledge and understanding that, in turn, would aid in the improvement of health for Pacific peoples.

4.3 Approach

4.3.1 Qualitative methods

This thesis takes a geographical approach to tuberculosis to understand Pacific peoples lived experience with TB. Qualitative research methods such as participant observation and semi-structured interviews were the main methods used. Semi-structured interviews allow interviewees to answer questions in any way they want which seeks to provide a better reflection of the interviewee's own thinking (Kitchin and Tate, 2000). The semi-structured interviews allowed me to consider participants' experience of tuberculosis from a social perspective rather than from a biomedical one, which as outlined in my introduction is the main aim of this thesis. From participants' recounting their lived experience of TB, an analysis of their verbal text surrounding TB and health can provide an insight into the process of the social

construction of those concepts. The questions were designed to encourage participants to talk about how TB has impacted and affected their lives socially as well as to elicit an understanding of the participants' beliefs and views on health, TB and traditional medicine.

In my approach, I used the Pacific Health Research Council's Research Guidelines (2004) for conducting health research with Pacific Peoples. Participants were exclusively Pacific peoples. Therefore, in interviewing and conducting focus groups with Pacific participants I tried to adhere to the ethical principles as summarised below:

- Relationships – build and maintain ethical relationships.
- Respect – demonstrate respect.
- Cultural competency – seek ethnic specific and context specific advice on culturally competent practice.
- Meaningful Engagement – effective 'face-to-face' consultation is critical.
- Reciprocity – build the health knowledge of participants and reimburse costs.
- Rights – recognise that participants must be properly informed in order to consent (Health Research Council, 2004).

As I will illustrate throughout this chapter and in the chapters to follow, these principles were considered in order to build a principled relationship and to promote a comfortable environment when interviewing and interacting with participants.

Advocates of Pacific research argue that research with Pacific peoples must use strategies that are Pacific in nature (Sanga, 2004) which are culturally inclusive (Nabobo-Baba, 2004). The very nature of this thesis topic necessitated that the research approach to be culturally inclusive. And because this research included participants from different Pacific ethnic groups I wanted to be considerate and respectful of the multi-ethnic cultural norms and values. For example when interviewing Pacific participants, I found myself thinking critically about my processes and relationship with participants from a Samoan perspective especially when interviewing those who were older than myself and who were male. I was always conscious of *fa'asamoa* and social protocols such as respect or *faaaloalo*

while at the same time, I was mindful that I could not let that intimidate me from asking the necessary questions. Anyway I was able to formulate a research approach that not only respected participants' points of view through meaningful engagement, but allowed participants to share their knowledge and experience on the research topic. One of the strategies which I found quite useful when interviewing male participants was to imagine that I was interviewing my own father, in that I needed to respect and recognise the rights of participants.

Throughout my interviews I tried to be sensitive to power relations especially when interviewing those who were not Samoan by trying to connect with my participants (Hoggart et al., 2002) in a Pacific way. What I mean by this is that I shared some of my own experiences as a Pacific person such as using traditional medicine so that they did not just view me as a researcher but a 'Pacific' researcher who understands indigenous ways of knowing so that they could feel they could talk more freely about their experiences. I found that after asking questions on traditional and cultural beliefs and practices I would sometimes get a long pause or a blank expression. To try and instigate a response I would recall a personal event or express an opinion relating to the question.

I kept a journal as suggested by Emerson (1995) to record meetings and field notes in a chronological manner. This journal contained all my field notes such as observations and comments following interviews and notes and observations from my participant observations from December 2004 (up until it was stolen when my car was broken into in October 2005, along with a couple of tape recordings and other material pertaining to my thesis). Thus, much of my observations from this period have been reconstructed from memory.

4.3.2 Quantitative methods

Another method used in this study was an analysis of secondary data from past studies to determine rates and trends for TB among Pacific people's in Auckland and also across the Pacific island countries over the last ten years (presented in Chapter two). The TB statistics for Auckland were obtained through the Auckland Regional Public Health Service. The data for these statistics from 1995 to 2005 provides a numerical

illustration as to how TB is affecting Pacific populations in Auckland both currently and historically. From Samoa I also obtained data from the TB specialist at the National Hospital in Samoa. The data is on TB cases from 1995 to 2003 and acts as a comparison to for the Auckland data. I also acquired TB statistics for the Pacific Region was obtained from the World Health Organisation Tuberculosis country profiles. This data helped to illustrate the spread of the disease across the Pacific and whether the resurgence of TB is typical to the area or whether it is more prominent in specific island nations. These statistics however are not as comprehensive as those obtained for Auckland and Samoa and so a through comparative examination into cross cultural comparisons for the above island nations was not feasible.

4.4 Samoa

In April 2005 I travelled to Samoa in order to conduct interviews with health professionals and TB patients. In January and February 2005 I prior to leaving for Samoa, I contacted, the National Hospital in Samoa and informed them about my study and my planned visit to conduct my research in Samoa. I wanted to make sure that I was made aware of any necessary requirement that would assist me in carrying out my research. So when I left for Samoa in April, I was quietly confident that I was in a good position to be able to gather the relevant information needed relatively quickly. I assumed that if there were to be any minor setbacks that I would be able to deal with them, and I was also mindful of my own status as a Samoan and therefore an 'insider' researcher.

On my first day of fieldwork I was seriously set back when I went to my appointment with the Samoan TB specialist and he informed me that I needed approval from the Samoan Research Ethics Committee if I wanted an interview. I explained to him that I had been planning this trip since January and that I had specifically enquired with the doctors and faculty members at the hospital whether there was any research permit or other such processes that I had to go through prior to my arrival and been told this was not the case as my research period was only for two weeks. If I intended to conduct research for more than six months, then I would need a research permit. Further, I had been in contact with another Samoan researcher from New Zealand

who had done research in Samoa recently to see if I required any permit or other paper work and he informed me that this was not the case.

The TB specialist was adamant that I needed approval from the committee or the chairperson before I could officially interview him and so he only gave me the name of the then chairperson of the committee who happened to be a fellow doctor. At first I could not find the chairperson so I began ringing the Samoan Ministry of Health to get the contact details of the Research Ethics Committee but no one knew of such Committee. I then tried calling the Ministry of Education and Foreign Affairs and nobody in those two ministries could help me either because no one knew of such a committee. The Research Ethics Committee was becoming an enigma. I tried to contact the TB specialist and the chairperson yet again over the next two days but to no avail. My situation was not helped by the fact that at this time the doctors at the hospital were going on strike and the Ministry of Health was also dealing with a corruption scandal.

I finally managed to track down the Committee Chairperson and after a short meeting he denied my request to interview the TB specialist stating that in the past, outsiders who have come to Samoa to conduct research have painted Samoa in a negative light. This I understand as many Pacific indigenous researchers argue that Pacific peoples are often dissatisfied with the representations of the Pacific made by the 'Other' (Nabobo-Baba, 2004; Smith, 1999). I tried to explain that my research was *about* and *for* Samoan people. I reminded him I myself am a Samoan even though I am not a Samoan national. Further, I stated that my research is trying to help with the treatment of TB and reducing TB cases which are one of the three primary goals stated by the Ministry of Health on their website. But because my research is associated with the University of Auckland, I found myself being the wrong type of Samoan. This clearly illustrates Anae's (1998) argument that being born into a certain ethnic group does not guarantee you 'insider' status in research (cited in Williams, 2004).

With the aid of a family member who happens to be a civil servant I was able to speak to a retired TB specialist. Through him I got into contact with one of the senior nurses who administer DOTS for the hospital. Although I was unable to interview her formally she gave me an insight as to how DOT is administered in Samoa as well sharing some narratives on some of the more unusual TB cases in Samoa. The nurse

informed me that Upolu is divided into seven health districts and one of the health districts is the urban area of Moto'otua. At the time Moto'otua had six cases. She was able to take me to interview these TB patients at their residence. One patient was an index case in a family where four family members were undergoing TB treatment. The index case was a 52 year old mother and the other three patients were children taking preventative medicine for TBI. Her other case was a 13 year old school girl. The nurse first explained to them about my research and then after gaining verbal-agreement I gave them an information sheet and consent form written in Samoan. When giving their verbal-agreement to the nurse they looked at me a bit hesitantly but after reading the official looking documents I gained more credibility and they were even more eager to participate when they realised I could speak and understand Samoan and that they did not have to speak English.

I conducted semi-structured audio taped interviews. With the two patients and I found that the older female was more open and forthcoming, talking freely whilst the school girl was rather shy and answered with only a few words. The questions asked followed a chronological order in terms of their illness starting with diagnosis and how had they come to realise that they had TB. This was then followed by a line of questioning about treatment and which health professionals were consulted. Next were questions about the impact that TB has had on their social lives. Participants were given an opportunity to ask questions at the end or make any final comments. The interviews were completed with a monetary *meaalofa* or offering to thank them for their participation. This is important especially when interviewing Samoan participants in Samoa who are my senior as this shows *fa'aaloalo* or respect to my elders.

I ended my trip by interviewing two *fofo*. Both *fofo* lived in the urban area and were selected because they were well known by the locals. They did not wish the interviews to be recorded and so I made jottings. One *fofo* proved to be a special find as she had studied at the University of Otago and subsequently gained a Bachelor of Science. On returning to Samoa she declined to take up a western medical profession and instead followed in her ancestor's footsteps and took up *fofo*. Sulu (not her real name) is quite fluent in English and chose to conduct her interview in English.

4.5 Auckland

4.5.1 Interviews

Every TB case is reported as part of New Zealand's system of national tuberculosis surveillance. Each TB case contains general information which includes ethnic group. Those who were invited to participate in my study indicated that they were of Pacific ethnicity. Participants were contacted through Public Health Nurses in Auckland. The nurses were given information sheets about my research which they would pass on to their patients if they agreed to participate (see Appendix). The nurses would then pass on their patient's contact details to me so that I could arrange interview times. Despite the help from the nurses I had limited success in acquiring participants as most patients declined to participate.

From May to November 2005 I conducted 11 interviews although not all the interviewees were TBD patients. Those who did have TBD were all recipients of DOT. I made sure that participants had read the information sheet either before I arrived or before the interview began and then gave a brief introduction about myself and reiterated that my research was of a social science nature rather than biomedical in orientation. I also ensured that the participants signed the consent forms. These consent forms caused much suspicion from quite a few of my interviewees. Although I explained in my information sheet and before the interview began that they would remain anonymous at all times and that I would be the only one who knew of their identity, they were still uncomfortable about signing the sheet. I tried to explain clearly that the ethics consent form was a measure of protection for both them and me. Many felt that their anonymity would be jeopardised by signing the form. At the end of each interview each participant was given the opportunity to ask questions or to make any final comments if they wished. All but one participant agreed to be tape recorded. All interviews were conducted at the participants' residence. All interviews were transcribed verbatim.

In one case I was able to observe the public health nurses administering DOT to a Tuvaluan family in which there were both adults and children involved. This opportunity proved to be enlightening as I was able to observe the relationship

between the public health nurse and her charges as well as observing the patients' reactions and demeanour throughout the process. I had discussion with the nurse about how tuberculosis has affected this family's life as well as gaining an insight into this small island community in regards to some of the politics that are occurring and how this has impacted on the nurses.

The following table gives a brief description of my participants. Pseudonyms are used for all participants to protect their privacy.

Table 4.1: Characteristics of Pacific TB participants

Name	Ethnicity	Age	Gender	Type of TB	Residency Status
Sina	Samoan	64	Female	Pulmonary	39 years
Leilani	Samoan	28	Female	Extra pulmonary	NZ born
Pepe	Samoan	64	Female	Pulmonary	8 years
Petelo	Samoan	52	Male	Extra pulmonary	Samoan national
Luke	Samoan	30s	Male	Extra pulmonary	NZ born
Paul	Samoan	77	Male	Pulmonary	44 years
Sione	Tongan	32	Male	Pulmonary and extra pulmonary	8 years
Tara	Cook Islander	34	Female	Pulmonary	5 years
Mere	Cook Islander	79	Female	Pulmonary	18 years
Sarah	Tuvaluan		Female	3 year old son has pulmonary	7 years
Mataeo	Tuvaluan	50	Male	Pulmonary	7 years
Teuila	Samoan	13	Female	Pulmonary	Samoan national
Luisa	Samoan	52	Female	Pulmonary	Samoan national

4.5.2 Focus groups

Two focus groups were conducted, comprising community members who were not TB patients nor related to any TB patients. The main aim of these focus groups was to try and gather understandings of health and TB. The first of two focus groups comprised of a group of five males and three females between the ages of 40 and 52 years from my church, Sulu O le Ola Manukau. The session started off tentatively so I began telling them about what my experience and knowledge of TB was before I started the study and then slowly they began contributing their thoughts and recalling their past experiences with TB. The dialogue was very free flowing and often they dictated where the conversation was leading which was pleasing for me as they were addressing my queries without me even asking the questions.

My second focus group comprised of four young people of Samoan descent between the ages of 19 and 20. There were two females and two male. This group's purpose was to gather their understanding and past histories of tuberculosis from the perspectives of a younger generation compared to my previous focus group. Although this group had no qualms or hesitations in talking, unlike the first group the dialogue did not naturally progress from one topic into another. It was more of a situation in which I would ask a question then they would answer and wait for the next. Both sessions were tape recorded. This allowed me to observe their interactions with each other and as a group and to observe their reaction to certain topics. Like the individual interviews, both focus groups were transcribed verbatim, by myself.

4.5.3 GP Tuberculosis meeting

During the time when it was difficult to find participants I was invited to the 'Peer Group Meeting on Tuberculosis and Diabetes for Pacific General Practitioners' at the Langimalie Centre in Onehunga. This was an opportunity for me to meet some Auckland GPs who mainly dealt with Pacific patients. The session began with Dr Craig Thornley giving a public health presentation on tuberculosis which was followed by a question and answer session. This gave me great insight into the process of how doctors would try to test for and diagnose tuberculosis as well as outlining the difficulties that doctors have in administering tests for tuberculosis. The session also raised issues in relation to administrative work especially in regards to

issues over residency which seemed to be a key concern of many of the doctors. The doctors were finally given the opportunity to present TB cases of their own which was interesting as each case was different.

Two cases that stood out for me were cases of delayed diagnosis as only one of my participants had experienced this eventuality. The first case was of a Tongan male who had several medical conditions which caused his tuberculosis to be masked by these other illnesses. After undergoing several examinations and tests the man and his doctor were surprised to find that he had, in fact, acquired tuberculosis. The second case involved a young child. The child's parents were concerned with an abscess that had begun to grow. After the initial treatment it went away but kept returning. On their third visit the doctor decided to have it examined and they found that the child had in fact extra pulmonary tuberculosis.

Although I had met these doctors during the meeting, trying to arrange a time to meet them after the meeting proved difficult. I tried to get in to contact with the doctors who had presented cases over a period of months to see if I could interview their patients. My details were also forwarded on. However, unfortunately I never received any replies pertaining to interviewing their patients although I did receive emails in acknowledgment of my requests.

The meeting had been on the 29th of June and after waiting a week to hear back from the doctors I decided to contact them myself as I was aware of how busy they are and presumed that they may have forgotten. I tried to contact a couple of the doctors whose cases and patients were of value to this study by telephone but I was unsuccessful and so I sent a series of email communications between the 26th of July and the 6th of September. During this time I also tried phone contact. I found that the doctors did not keep a normal Monday to Friday, nine to five working week and were only available at the clinics at certain times and on certain days. However, during these times they were too busy to field phone calls or return my messages. By the end of September I decided to end pursuing the doctors after eight weeks of unsuccessful attempts.

4.5.4 Participant observation

While in Samoa I was often asked if I was on vacation. I replied that I was studying the social aspects of TB. To this, the response was generally that the novelist Robert Louis Stevenson brought TB to Samoa in the late 1800s. The way they nonchalantly expressed this view was interesting as it reveals how some Samoans regard TB as a disease of the 'other' much in the same way that Western societies do. Also, in general most people were intrigued as to why I was studying such an obscure topic, as they did not realise just how prevalent and relevant TB is today.

In Auckland and amongst my own social networks, people were more afraid that I might 'catch' the disease. They asked why I would want to study such a topic in an attempt to dissuade my focus on TB to other 'safe' topics. Peers of my age group upon learning that my study was on TB actually thought I was studying the decline and almost non-existence of TB. When I corrected them and informed them, that actually the reverse is currently happening they had no idea that TB is a worldwide phenomenon. Further, most of the younger people who knew I was studying TB commented on the BCG vaccination and how it left such a big ugly scar. Thus, I realised for younger people there is a common experience where not much is known about TB and that their experience of TB is only limited to the BCG vaccination. For the older generation whom I had regular contact, their concern and fear surprised me at first but upon further research into TB and the Pacific I came to understand that their sentiments reflect the stigma surrounding TB. This will be discussed in more detail in my two analysis chapters that are to follow.

4.6 Summary

This chapter outlined two important aspects in researching Pacific peoples in New Zealand: firstly, the approach in which a Pacific perspective is required; and second, an investigation into the identity of the researcher. Because some Pacific people feel they have been over-researched it is important to be sensitive when conducting research with Pacific communities. It is important that those being researched feel that the research provides implications which can enhance and improve their health outcomes. A description and explanation into my approach and methods used, were outlined in order to illustrate the questions posed by this thesis: what is the health

seeking behaviour of Pacific TB patients; how cultural identity and health belief impact on this behaviour and how community and social networks are utilised were investigated. The decision to undertake interviews and focus groups was focused on a belief that these methods allow an analysis in the social construction of health and TB and also how their identity and sense of place has influenced these constructs. Finally, having to defend my identity often left me in an unenviable situation where I feel that I'm not the 'right Samoan' to be doing research with Samoans anywhere. Thus positionality or outsider versus insider status became a key issue throughout the field work process.

Chapter 5

Talanoaga: Health Narratives

“Having TB, man, you have no idea man. I tell you, it’s horrible.”

5.1 Introduction

As I have illustrated in Chapter 2, which outlined a Samoan health framework, lifestyle, cultural attitudes and social values and mores help to shape and structure a community’s understanding of health. In this chapter I analyse the transcripts of interviews that I conducted, according to the Health Research Councils guidelines for conducting Pacific research. This chapter is organised according to stages in the illness process: the self diagnostic stage in which participants describe how they came to know they were ill, and the diagnosis stage during which they seek outside help to discover what is wrong with them, and finally the diagnosis of tuberculosis and how this impacted on their lives. The chapter concludes by analysing the participants’ views and experiences with western medicine and traditional medicine.

5.2 The diagnosis process

5.2.1 *Feeling ill*

As outlined in Chapter 1, TB infection is caused by the tubercle bacillus. However, TB infection is necessary, but not sufficient, for the progression of TB disease. TB disease can either be pulmonary (in which it is located in the lungs), extra-pulmonary, (in which the bacteria has moved outside the lungs) or a combination of both. Depending on whether the disease is pulmonary or extra pulmonary it can manifest itself in various ways. The symptoms of pulmonary TB include a persistent cough, weight loss and night sweats while for extra-pulmonary TB the most obvious symptom is a growth, especially around the lymph node areas (World Health

Organisation, 2005). For this reason the narratives and experiences of those with extra pulmonary TB are often different to those patients with pulmonary disease.

For most people, feeling ill or sick is a deviation from a desired or normal state of wellbeing: physically, mentally and emotionally. An individual who is feeling ill goes through a process of self-diagnosis to determine the cause of this feeling. For two participants with extra pulmonary TB, Luke and Leilani, TB had caused growths like an abscess on their bodies and so, although they were not feeling unwell, as soon as the growths occurred they immediately sought medical advice. However, for those with pulmonary TB there was a delay in seeking medical attention. Many of the patients had experienced cold sweats, loss of weight, loss of appetite and a persistent cough. Despite these symptoms many of the participants waited until they deteriorated further until either they could no longer handle the pain or family members insisted they sought medical advice. Often, this wait lasted months as some participants relay,

“I had been ill for awhile, ah, not knowing I had TB.”

Petelo

“...I lost a lot of weight, didn't want to eat, drink. I had no energy. I was ill for about three months before (seeking medical advice).”

Sione

“I had been sick for quite awhile...I must've been sick since last year...probably started in umm, I think March that's when I had the conflict of umm, coughing quite a lot.”

Tara

Tara and her family had noticed her ill-health since March but it was not until December that she was actually diagnosed with TB, and began treatment. Mataeo's story is similar to that of Tara. He had been ill for quite some time but had delayed seeking medical attention. What was most unfortunate for both Tara and Mataeo is that the delay had meant that they had passed on the infection to those in their households. Four children in Mataeo's household consequently were infected. Unfortunately, the infection progressed into disease for two of the children. Now, two of the children are on medication for TB disease and the other two are receiving treatment for TB infection. In Tara's household three children were infected and the

youngest child was five months old at the time. For Tara this caused a lot of guilt and regret.

“... during that time when I had been very unwell, umm, but not realising I actually had TB but at the same time that I was actually spreading it around my family members...so when I was diagnosed with it they had to check my family and the children was infected more and, and I was very, very upset about that...but I should've known that um, there was something really, really wrong with me.”

Tara

5.2.2 Self-diagnosis

Despite feeling ill and having persistent physical symptoms, many of the patients delayed seeking medical attention. Often this resulted in dire consequences. However, the participants' narratives suggest that if they had known that their symptoms were actually caused by something quite serious such as TB, then they would not have waited so long to seek health advice. The reason why these participants delayed seeking any medical advice lies in the process of self-diagnosis. Most participants when feeling ill self diagnose, and more often than not, guess the cause of their illness and apply remedy that is based on their guess (Helman, 1995; Drozdow-St Christian, 2002). Further as Drozdow-St Christian (2002) discovered in Samoa, Samoans often try to hide their illness from others from a fear that the illness maybe perceived as a consequence of a social impropriety by the patient or a member of the patient's family. It is interesting to note that with most participants, the cause of their symptoms before realising they had TB, were related to their lifestyle. For example, Sione believed that excessive eating and drinking since arriving in New Zealand caused his illness,

“I thought I was getting sick by eating too much in New Zealand, especially bad food (and) from drinking too much rum.”

Sione

Luke believed his illness was a result of the stresses that he was under at the time, indicating that emotional stress is a factor that led to the onset of TB disease. Luke's perspective follows an ecological approach in understanding the epidemiology of disease. At the time, he had been living away from home in a hostel and was having

issues at work. Consequently Luke found himself caught up in a bad situation with substance abuse, as his story illustrates,

Roannie: Do you have any idea of how you got it (TB) then?
Luke: I don't know if it had come through 'cause of stress and stuff
Roannie: Yeah...
Luke: It does, yeah that was probably a big factor then...cause I wasn't living at home
Roannie: And that was stressing you out?
Luke: Yeah, work and where I was living
Roannie: All that stuff, oh I see
Luke: And a mix of something else!

Thus, Luke's belief that his illness was not the consequence of biological factors but social factors strengthens the argument made by social scientists for more attention to social parameters that can influence the epidemiology of disease (Mayer, 2000; Gatrell, 2002).

Tara had been born in the Cook Islands but has travelled back and forth to New Zealand over the years and often stayed in New Zealand for months at a time. In 2000, Tara decided to migrate permanently to New Zealand from the Cook Islands and believed that her illnesses were related to the changes with migration and adjusting to New Zealand's lifestyle and weather as she explains:

"But I have been sick for quite awhile, especially coming back to New Zealand from the Cooks, change of weather, change of everything. Um, I wasn't so used to it."
Tara

Tara's comment supports the arguments made in Chapter 3, where other studies indicate that migration can cause ill health and highlights the need for more research into the relationship of migration and transnationals (Elliott and Gillie, 1998; Acevedo-Garcia, 2000). Her words clearly illustrate that she found it difficult to adjust to her new environment which caused illness. Further, Tara had not brought the disease with her into the country but she had in fact caught the disease in New Zealand, as established through contact tracing. It is now common knowledge in public health circles that for Pacific migrants, most infection takes place in New Zealand (Carr *et al*, 2001). This fact needs to be made more explicit and widely

promoted to dispel the common belief that migrants are bringing TB into the country. In New Zealand, like other developed countries, host populations view TB as an exotic and imported disease (Gatrell, 2002). The complexities of migration, health and TB will be explored in more detail in the following chapter.

5.2.3 *What's up doc?*

Unlike Pakeha TB patients (Searle, 2004) eight of the 11 Pacific participants were diagnosed quickly with TB after seeking medical advice. This may be because Pacific peoples are viewed as one of the ethnic groups most likely to contract TB and so are tested TB almost immediately when symptoms for TB arise. This is in accordance with the Guidelines on tuberculosis control 2003 in New Zealand (Ministry of Health, 2001). In Searle's (2004) study of Pakeha, delayed diagnosis caused serious health problems for two male participants over 40 years of age. One participant waited for a year before he was diagnosed correctly while astonishingly, the other did not get diagnosed until two years later. In the *New Zealand Woman's Weekly*, an article was published on a Hamilton Pakeha woman's experience of TB as a prime example of delayed diagnosis. Her GP had told her that she wasn't tested earlier for TB because she did not fit the criteria for those at risk, that is, as he specifically stated, that she was not a Pacific person (Mulu, 2005). Further, all newborn babies of Pacific Island descent are given the BCG vaccination (Ministry of Health, 2003). This policy illustrates just how strongly TB is associated with 'other' ethnic groups and not the dominant ethnic group, Pakeha.

Tara, Luisa and Sione were the only participants who experienced delayed diagnosis and who did not have any other medical conditions to mask TB. Sione waited three weeks as doctors initially thought that he had kidney problems before he was diagnosed with both pulmonary and extra pulmonary disease. Over the course of almost a year Tara had a persistent cough. She visited her doctor four times and it wasn't until the fourth visit when she insisted on having a full examination that they realised that Tara had TB. Tara's story is similar to that of Luisa in Samoa, who had a persistent cough for almost a year. Like Tara, Luisa had also suffered from loss of appetite and significant weight loss. Luisa went to Samoa's hospital a number of times without being diagnosed with TB. The younger participants in Auckland, that is,

those under 40 years, experienced delayed diagnosis. However, statistics show (refer to appendix) that those between 25 and 39 years have higher rates than the older age groups.

“Ua fiu foi ou te alu I le falemai e aumai ou vai kale. Pei ua sefulu ou vai kale e leai a se suiga.”

Luisa

Translation: I was constantly going to the hospital and only getting cough medicine. I had about 10 different cough medicines and there still wasn't any change.

A couple of the elderly participants had similar experiences to the Pakeha in Searle's (2004) study whereby other illnesses masked TB. Mere, an elderly Cook Island woman had been in and out of hospital. At first, the doctors thought that she had pneumonia but after treatments were unsuccessful for pneumonia they finally realised that she had TB. This delay, however, meant two of Mere's nieces were infected and they both were put on preventative medication for TB infection.

Malia suffers from diabetes and when she began collapsing, her doctor thought that it was because of her diabetes. However, after a severe fall Malia went to the hospital and within three days the doctors at Auckland hospital diagnosed her with TB. For my Pacific participants in Auckland, delayed diagnosis is more of an issue for the elderly who suffer from other medical problems, indicating the association between TB disease and those who are immunosuppressed (Ministry of Health, 2005).

5.3 What? TB...

5.3.1 The reaction

The initial reaction from participants when they were finally diagnosed with TB varied significantly depending on commonly held construction of TB in the past, and whether or not the participants had had any experiences earlier with TB. Health culture is the term used to define the past experiences within a cultural context to refer to 'understanding and information people have from family, friends and neighbours as to the nature of a health problem, its cause and its implications' (van der Oest, 2005).

For those such as Leilani, Mere and Teuila finding out that they had TB was not a big issue for them because prior to becoming sick they had no idea what TB was.

However, for some of the other participants finding out that they had TB came as a shock and surprise. In fact when Makelita went to hospital to check on her husband Paul and was told that he had either TB or cancer, she was shocked that he could have TB and even hoped that he had cancer instead of TB.

“There were two things they were trying to find out, if it’s TB or cancer...So he said to me ‘they said that they hope that I got TB’. (and I said) why, why.”

Makelita

Makelita’s reaction was mainly due to her past encounters that will be discussed later. Interestingly, the same scenario occurred in Searle’s study (2004) in which a patient had, in fact, hoped that the illness was cancer instead of TB.

Sina is an elderly woman who is also a diabetic. She had a couple of blackouts which she believed to be related to her diabetes, thinking that she may not have had enough to eat. Many of the elderly patients, who also have other illnesses, become very surprised to learn that they have TB, rather, attributing their ill health to other existing medical conditions. In Sina’s case, after having thorough examination at Auckland Hospital she was informed that she actually had TB.

“I was very surprised when I was told that there was TB, very surprised.”

Tara’s reaction to TB was also one of surprise and shock. Not only had she had an emotional knock on finding out she had TB, but her experience in hospital during her isolation period having to wear a mask also put Tara under immense emotional and mental pressure. This is Tara’s story,

“When I was diagnosed with TB last year, yeah, it wasn’t something that I handled very well...having TB, I tell you its ah, to me it’s a very embarrassing thing...when I was in hospital people would look at you like you were a freak. They won’t look at you as a person, they will

look at you, you are a walking disease...it was never easy when I was in hospital, not when you're walking around in a mask."

Tara

Tara was also critical about the bedside manner of the specialists at Auckland hospital and made an interesting point about how specialists talked to her. The type of language they used did not ease the struggles she was going through, but in fact exacerbated them.

"Yeah, they (specialists) love using that word, 'you're contagious' and it make you feel even insecure inside and I think, bloody hell... Strong, strong words aye"

Tara

Tara's concern with the 'you're contagious' comment made by some specialists at hospital shows obvious distress where illness can impinge on a person's identity. The impact of illness on a person's identity can impact greatly on their self esteem and can cause emotional and mental distress. Tara not only had to come to terms with the fact that she is a TB patient, which in itself can be very distressing, but she also had to endure the reality of being a *contagious* TB patient. Discourse related to TB and careless use of words such as 'contagious' can, to some extent, be accountable for the way that TB is stigmatised today. Language therefore is important in people's experience of illness.

Language is important as it is the way we communicate but language has different meanings and associations for different people depending on the context (Gesler and Kearns, 2002). In Tara's case, the use of the word contagious, at least for the doctors, is just a technical term or medical jargon with no malice intended. For Tara, the word 'contagious' aroused negative connotations as well as a personal label.

5.3.2 Health culture and stigma

Many Pacific people over 40 years of age have heard stories about TB that are often surrounded by fear, terror and stigma. People of this age group grew up in a time where TB was one of the leading causes of death and, as such, there were many campaigns to try and eliminate the disease and the fatal effect of TB. van der Oest et al's (2005) study of TB beliefs among migrants in Waikato echoed these sentiments

among the older generations of Pacific peoples because of the levels of stigma in relation to TB. It appears that generations have not been re-educated about TB and the advances that have been made, which make TB an easily curable disease in its simple form as long as the patient does not have multidrug resistant TB or if they are not immunosuppressed.

Many of the participants who grew up in Samoa have stigmatised images of TB. This is due to the way in which TB patients were treated in Samoa. Fear of TB was instilled in people in Samoa and this fear was further legitimised by the practices associated with treating TB patients that were common prior to 1980. From 1921 to 1960, the US Naval Medical Department began an aggressive TB control campaign in American Samoa where non-cooperative and contagious patients were forced into isolation by the legal system, with few visitation rights for family and friends (Ah Ching et al, 2001). One of the participants from the focus group recounts what happened to her friend's uncle who had TB:

“Umm, yeah Ranie, he was isolated, tusa la e ese le mea na nofo ai⁸. He had his own separate room away from the house where he would stay. And when the kids took his meaai⁹ they would run there and run back fast and no one was allowed to touch his sipuni ma mea faapena¹⁰. E fufulu ese a aga mea ma aga ie afu ma mea faapena na susunu¹¹. Yeah, nobody allowed to touch him or see him...”

Elisapeta

Makelita also shared a similar story which explains why she would have rather her husband, Paul, had cancer instead of TB,

“So they said to me they said that they hope that I got TB. Why, why because I was thinking when I was in Samoa...it was a what you call a very contagious TB and people are living on their own in the other place and no one allowed to go...But when I went there (hospital) I was shocked and then he said to me that the doctor told me that it's better if I have TB because its curable...and I said 'Oh I never knew that there was medicine for cure for TB'.”

Makelita

⁸ He stayed in a different place

⁹ food

¹⁰ spoons and things like that

¹¹ His things were washed separately and his clothes and stuff were burnt.

That Makelita never knew that TB has a cure illustrates the lack of knowledge older people have of TB and partly explains why TB is still stigmatised. One male participant from the first focus group also highlighted this point in an interesting manner,

Isaia: *you know, TB is like the same as lepela*¹².

Roannie: *Really? Why would you see TB the same as lepela when
the symptoms are so, so different.*

Isaia: *because they're both fatal; they have no cure.*

The above comments assist considerably our understanding of the stigmatisation of TB in Samoa. The matter-of-fact tone used to state that leprosy and tuberculosis has no cure implies that they this was and is still the case in Samoa. It highlights the need for re-education and raising awareness about tuberculosis. In Samoa there was a leper colony on an offshore island where people were forbidden to go unless they have leprosy. So, like the lepers, those with TB also had to suffer alone because the two diseases were the only diseases seen as infectious and incurable.

It is interesting to note that at present, the stigma associated with leprosy and TB is still evident in Samoa. Currently, at the Apia National hospital in Moto'otua, leprosy and TB services are situated at the TB/Leprosy Clinic. The combined clinic is now located at one end of the main hospital, whereas when they were two separate units, the two clinics were located at opposite ends of the main building. In 1999 the TB ward was closed because medical officials had determined that TB was non-existent, after which TB services were amalgamated with the leprosy clinic on the other end of the hospital compound.

¹² leprosy

Below is a picture of the TB/Leprosy Clinic signage, at the end of the main hospital building in Apia.

Figure 5.1: TB/Leprosy Clinic in Moto'otua Samoa



For some Samoans, illness can be traced back to some social disrepute. The seriousness with which TB and leprosy were viewed meant that the TB patient and or a family member must have seriously contravened a social custom or relationship with another being (Drozdow-St Christian, 2002). This can partially explain the stigmatisation and isolation of TB. The seriousness in which Samoans regard TB provides that the patient or the patient's family has breached a significant protocol. Therefore TB patients maybe kept in isolation in order to save the family's dignity and reputation from anyand cast any suspicion of wrong-doing by the family. This view clearly illustrates the pervasive ideas about health in Samoa where it is regarded as more of a social phenomenon than a medical one.

For Sarah and her family who come from a village on one of the smaller islands in Tuvalu, the fear of TB stemmed from the accounts of the missionary nurse who was stationed on the island. According to Sarah, the nurses had mentioned TB as being ‘scary’ which is why, when asked whether she was worried about TB when they first found out that her son had TB, she had this to say

“Oh yeah, because like it’s scary, but it’s ok now you know because its curing”

Sarah

Comparable with the views expressed within the focus group, Sarah’s concern about TB stemmed from the fear that it is incurable. Her story and health culture is also similar to views expressed within the focus group whereby participants remembered that it was the Palagi doctors who mainly spread the word about how devastating TB is, but they could not recall ever being told of a cure, only of a vaccination. How Sarah came to understand the concept of vaccination is unclear. These narratives also illustrate the arguments made in Chapter 3, about how health is a social phenomenon and that the understandings of health can be shaped through social processes and organisation.

Luke and Tara were the only two TB participants who experienced any stigma from their health status. Luke felt uncomfortable divulging any specific information but Tara shared some of those more unpleasant moments with people. Most of these encounters happened while she was at hospital and was wearing the mask,

“Yes. With um, it’s what people were saying, ‘argh, get away from me’, or you know, ‘you’ve got something contagious, I don’t want you near me’, and you start having this barrier.”

Tara

5.3.3 Fears

The doctors gave all the participants a clear understanding about TB and the fact that it is curable as well as contagious. Patients and their families were also given out little handbooks on TB which were published in Pacific languages. These resources informed and assisted the patients’ understanding of the disease and consequently with dealing and coping with the illness experience. There were two main fears that

participants had with the disease. Firstly, there was fear that the disease may reactivate or, in other words, come back again later on in life. Secondly, was the fear that the disease may still be contagious, and that, before diagnosis, they may have unknowingly infected others. This was the main concern especially for mothers like Leilani and Tara. As Leilani points out

“I’m just scared it might become contagious, or the boys might get it or something.”

Leilani.

5.3.4 Impacts

When asked questions on how TB has impacted on their lives, the participants commented that having TB had not impacted greatly on their lives. However, from many of their narratives and accounts once a diagnosis was made, many of them expressed emotional distress. Further, many of the participants, at the time of the interview, were nearing the end of their treatment course and so have had time to cope and adjust as a TB patient,

“Yeah, it’s become part of my life now, taking medication, that’s all it is...When I first came back home, it was, being frustrated just, by looking at those pills, sixteen of them and you just pop them back...But as time went on it’s like, ‘Hey, I’m gonna be stuck with it so I might as well make the most of it...Yeah it becomes a routine for me. I know what days they come and I know what time and I know how many medications I’m taking.”

Tara

Most of the participants noted that TB was more of an inconvenience because of the lengthy period in which medication has to be taken religiously and the specific times in which it has to be administered. Most participants, when asked if TB had caused them any difficulties or had disrupted their life in any way, said no. The two main concerns that arose although not shared by all were the issues of travelling to appointments and the time spent with appointments and doctor’s visits. Sione lives alone but has a large family living in Auckland. His main concern was job security as he feared that he might lose his job with all the time spent away on doctor’s visits and appointments.

For Pepe and Makelita, who are both pensioners, travelling to and from doctor's visits and appointments were a real issue because neither of them could drive. Transport costs to health service providers is also one of the problems that Dr Fuatai acknowledges, is facing Pacific people in New Zealand results in delays seeking medical attention (Ministry of Health, 2004). For example, Pepe had to rely on either the public health nurses or her children for transport. However, sometimes neither those sources could be available especially if appointment times could not be scheduled for when her children were off work. Sometimes, she and her husband would take the bus on the 25-kilometre journey. Makelita, and her husband who is 78 years old, was more fortunate because she was given taxi vouchers from the Auckland District Health Board. However, she did not appreciate the early appointments:

"I was really mad and beating my heart. We have to wake up every morning. It's hard for a over-60-year-old we have to wake up and make the breakfast and whatever and dress in the cold weather and then he have to come here (hospital)."

Makelita

This commentary illustrates some of the difficulties that elderly people face, especially when they are living off a pension and live on their own as Makelita and her husband Paul do.

TB has surprisingly made a positive impact on Tara's life as it has made her reconsider her lifestyle choices,

"TB was something that wasn't taken lightly. So I changed my whole life around of smoking and drinking and tried to get myself better, think about my health wise."

"I mean it's just you look at things in a better perspective. This year's seemed to be the year that I started changing my whole life around. Since the day that I had TB."

Tara

For Tara having TB has been a turning point in her life. She has now chosen to live a healthier lifestyle and nurture her spirituality by becoming a church member of the Latter Day Saints of Jesus Christ. She has also recently moved in to her own house with her son. Tara's story provides a more positive and enlightening aspect to TB

where this disease is often marred with negative connotations. The existential implication of illness, are well noted in the health geography literature where serious and chronic health events have led to a dramatic positive change in lifestyle (Gesler and Kearns, 2002).

5.3.5 Treatment

The experience of isolation in hospital is one of loneliness, as the patients have little else to do but to contemplate their fate. For Pacific peoples family is extremely important especially as they provide emotional support that can help the patients cope and adjust with their situation (Stansfeld, 1999). The emotional and mental stress that patients go through while in isolation should not be underestimated. Although at present there is no other solution for managing contagious patients to prevent further infection or outbreaks, doctors and hospital institutions need to be aware of the sensitivities with a patient's emotional and mental state. Tara recounts her experience during her time in isolation and her observations about the other patients, who unfortunately did not have a lot of visitors for support,

“Yeah, and I was a bit conscious about that, wearing a mask aye, you know, um I mean, if you were in my shoes walking around a hospital wearing a mask and everybody else is looking at you...But in the process, with, um with other patients who also had TB, and every one of us were all different, and the ones who had been there a bit longer than I have, you know, its sort of like, um, I'm not alone in this. But watching them struggle mentally and physically it was like ooh, thank goodness I'm not going to be like that...Mentally, it's more of a mental thing you know, to try to get over it.”

Tara

Paul also felt that the hospital was no place to facilitate his well-being. Makelita had objected to him coming home because of her own personal fears and had wanted Paul to stay in hospital to recuperate.

“Paul said to me, ‘Makelita, I wana come home. 18 days here is too long and I'm starting to feel weak and if I come home I be ok and I'm free to walk around, do what I want around on my own.”

Makelita

During the time the interviews were conducted, all participants were receiving DOT. Luke had initially been on self administered therapy but was then placed on DOT by his doctor after he failed to keep up with his treatment regimen. It is imperative for patients to adhere strictly to their treatments, otherwise, their TB can progress to the more severe form of MDR-TB. This type of TB is complex and takes longer to treat and is more expensive (World Health Organisation, 2005).

Treatment is viewed as a necessary evil and patients appear to accept the fact that a multitude of drugs need to be taken over a long period of time. Thus, participants did not have any really negative comments about treatment. Instead most participants took a positive approach to treatment in order to get better.

“Ia ou te toaga e inu ou fualaa ou te toe malosi ai.”

Luisa

Translation: I am diligent in taking my medication so that I can get better.

DOT ensures that patients are taking their full course of treatment but for some of my participants, taking responsibility to get better is essential as it gives them a sense of power and control over the disease and their body.

5.4 Medical pluralist themes

5.4.1 Western medicine versus Traditional medicine

Ministry of Health (2004) data shows only three percent of Pacific peoples have used traditional healers. However, I believe this is an area of significant underreporting in which Pacific peoples are choosing not to state they have seen a traditional healer. Many studies have indicated that a large proportion of Pacific peoples use traditional medicine in New Zealand (Kinloch, 1985; Tukuitonga, 1990). van der Oest et al's (2005) latest study shows that traditional healers are used by many and that this is intensified by structural limitations in accessing health care.

In my study, only three out of the eleven participants had not seen a traditional healer with eight participants reporting they see traditional healers on a regular basis. Three

participants opted for a traditional healer when they first became ill with TB, without knowing it was TB at the time.

Sione was one participant who went to see a traditional healer first before seeking a GP through relatives as he indicated that he had problems with accessing a GP on his own,

“I only went to see one healer once, he lives in Otahuhu. There were heaps of people at the healer...Then I went with my uncle to see the doctor.”

Sione

The eight participants who see traditional healers on a regular basis also have regular doctors that they see as well. But more often than not these doctors attend Pacific primary health care clinics where the doctors speak Pacific languages and understand the context and living situations of Pacific peoples well. For Sarah and Mataeo this is the main reason why they chose to see a Pacific doctor. Because their doctor is of the same ethnic group they feel a lot more comfortable as they realise that their doctor can understand their worldviews and can relate well to them.

Macpherson and Macpherson (1990) argue that the Samoan medical framework does not dismiss western medicine at all but rather, Samoans like to adapt that which works for them from the western health framework. Luisa’s statement on western medicine and traditional medicine and Petelo’s comment on healing illustrates this point,

“O o lou fuafuaaga I ai o vai ou te inu ai, o le vai ou te manuia ai po o le vai samoa, po o le vai falemai”

Luisa

Translation: My belief is that I’ll take the medicine that makes me better, whether it be Samoan medicine or medicine from the doctor.

“Well being a Samoan and all, ah, I don’t see anything drastically bad about Samoan medicine and that...I feel that you know healing is a God given thing and ah, you know, God can work and can perform those types of medicines too.”

Petelo

Thus for Samoans, the choice of health framework is dependent on the success of treatment. As Teuila points out, the medication that the hospital provides is working best for her,

“Ia o lou manatu I ai o le a foi e sili atu le vai mai le falemai ou te malosi ai, a o vai iinei e moi a, ae le malosi ai au le mai.”

Teuila

Translation: I believe that the medicine from the hospital make me well again, the medicines here (Samoa) are still good in all but they don't help to make me well again.

My participants believe that both models of health are legitimate and do not view one as being superior to the other. Most of the Pacific participants living in New Zealand have a dual health framework in which they use both health frameworks regularly and move between the two systems easily utilising the framework which best fulfils their needs. For my New Zealand-born Samoan participants, their views on traditional medicine differ. Often western medicine is seen as superior and traditional medicine is seen as 'backward'. Leilani explains that her mother had wanted her to see a traditional healer; she was not so keen on the idea,

“Oh I think that like the English medicine is a whole lot better than the Samoan ones...when it comes to the medical stuff I just like the experts.”

Leilani

This sentiment is also shared by members of the second focus group of young Samoans who believed that Western medicine and doctors are superior to traditional healers as they have undergone specific and rigorous training at prestigious institutions. This is unlike traditional healers, as Leonie comments

“...they learnt their medicine from you know outside in the backyard from their parents. It's not like their real job it's just something they grew up with”

Leonie 19 years

This response demonstrates a level of acculturation through which these young New Zealand-born Samoans and Cook Islanders view traditional paradigms through western cultural perspectives of health, biomedicine and science.

5.4.2 Traditional healers

My research supports the claims made by Macpherson and Macpherson (1990) that traditional healers often delineate whether a person is suffering from a *ma'i samoa* or from a *ma'i palagi*. If the illness is caused by a *ma'i palagi* then the healer will tell the patient to see a doctor. For instance, when Sione visited a traditional healer he assessed Sione and then advised Sione to see a doctor straight away. Tasi, a traditional healer in Samoa informed me that if she became aware that she would be unable to treat her patient then she would advise them to seek counsel elsewhere and, depending on her assessment, she would either recommend a doctor or another healer.

Mataeo, a Tuvaluan healer, stressed that his healing only related to Tuvaluan illnesses and readily acknowledged that his healing could not treat TB.

“the TB don't have cure, I don't think this one (Tuvaluan medicine) you have to soothe the pain for the TB.”

Further, Mataeo explained that the main cause of Tuvaluan illness is related to *fakasulu* which sounds similar to the Samoan *to'ala*. As discussed earlier in Chapter 3, the *to'ala* is a nebulous life essence that is located in the abdomen. Movement from its normal residing place causes a range of illnesses (Macpherson and Macpherson, 1990; Drozdow-St Christian, 2002). Mataeo comments that much like the *to'ala*, the *fakasulu* resides near the abdomen and although you can feel it with your fingers you would not be able to detect it using x-ray machines or scanners,

“... with this one (faka sulu) finding in the stomach, I can find it with my hand but if you go to the x-ray or scan they can't find that one.”
Mataeo

Sulu, one of the traditional healers I interviewed in Samoa, was wary and suspicious of the hospital but not necessarily of the doctors. It was difficult to elicit why she had such a deep suspicion and nervousness about the hospital that she would only refer to the hospital and doctors as 'them'. What made Sulu's suspicions even more intriguing was the fact that she has a Western education with a Bachelor of Science degree from Otago University. What I was able to determine is that she chose to practice traditional healing instead of furthering her career in western science because of her beliefs about Samoan culture and customs. She believes that western medicine

and the hospital have no place in Samoa, which is why there is such a high fatality rate at Samoa's national hospital. The common perception regarding the hospital in Samoa is that it does not facilitate wellbeing. This perception implies that the hospital should be the last resort in seeking reprieve from illness. Inevitably, as a last resort, only terminal cases would be sent to the hospital. Arguably, this can be viewed as a self fulfilling prophecy.

5.5 Relationships with health professionals

5.5.1 The doctors

Only Makelita and Tara made comments about doctors. For both, at the beginning of the relationship, they found the doctor-patient relationship tense. This was mainly due to the way the doctors delivered their news and the language that they used, as discussed earlier on with Tara's situation and her feelings of insecurity every time the doctor kept saying 'you're contagious'. Tara also had this to say about doctors and their 'medical talk'

"I mean, okay, doctors put it in medical terms, medical talk aye...you talk the way you talk and you just can't help it, you fix the problem right then and there and you fix the problem and you walk off and don't have to deal with it, or deal with that person again."

Tara

However, both participants came to realise that the doctors were only doing their jobs and part of their frustration towards the doctors was due to the fact that they were the bearers of bad news. After the initial shock and frustration Makelita was grateful and thankful to doctors in authorising taxi chits for transport and for explaining fully, every aspect of TB.

5.5.2 *The public health nurses*

From the interviews with participants I gathered that the public health nurses have a very strong relationship with their patients in terms of providing reassurance and support. For the patients this makes their treatments considerably more bearable and the participants have the utmost respect for the nurses and their jobs.

“Yeah you know if I had a job like that, you know doing um, medication every single day, you tend to have a little stress...they are very caring and I give credit for them.”

Tara

Because of the frequent contact that the nurses have with their patients they form a bond in which patients now view the nurses as their nurse, but also more as a friend.

“She’s just like a good friend. I don’t look at her as my nurse I just look at her as a mate.”

Tara

This friendship is vital especially when medication needs to be given regularly and at specific times so that patients feel free to tell the nurses about anything that may hinder their treatment. One nurse who has a few Tuvaluan patients found that trying to form a friendship proved difficult, but she did not give up and was firm with them. In the beginning she had a hard time trying to organise a routine for the family and she felt like she was constantly getting the run-around. In the end she has earned their respect and friendship so that now she has managed to establish a routine that suits both parties. She also feels more at home and comfortable with the family that she even jokes with them. The Tuvaluan family feel the same as they told me their nurse is now ‘part of the family’.

Pepe explains how her nurse has been a great help to her by not only providing much needed transport but also by reassuring Pepe and having a positive attitude. As she explains

“Ia, ia le public health nurse, o latou na lea sa help ia te au. O mai ia i le fale aso uma e faainu fualaau, ia ma ave foi au pe e fai mea o faaata

ma mea faapena.”
Pepe

Translation: The public health nurses have helped me. They always come to bring my medication and they also take me for my x-rays and things like that.

The public health nurses play a vital role in ensuring the success of DOT. As with the doctors, patients respond better to those who they feel care about them as people and not just as patients. Once friendships are made then the job becomes easier for the nurse and the treatment becomes tolerable for the patients. Seeing people as often as the nurses do through DOT provides an opportunity for most nurses to build friendly relationships with patients.

5.6 Conclusion

This chapter analysed participants' transcripts of their lived experience with TB. The narratives relating to causation of illness and TB disease show a holistic approach to health and illness. The fact that many of the participants believed that their illness was socially related before being formally diagnosed shows that people do not strictly view illness in a biological sense. Instead, the participants view illness in a holistic framework similar to the Samoan health framework outlined in Chapter 3. This analysis highlighted the importance of health culture to the social construction of TB. Past experiences of TB in Samoa, for Samoan participants, have precipitated the stigmatisation of TB. However, for some participants re-education with respect to the disease in Auckland and Samoa has meant a change of perception. Further, some of the accounts provide evidence for a relationship between place and the social construction of TB as illustrated by the Samoan TB and New Zealand TB discussion. The experience of TB can also create identity crises especially for TB patients who are deemed to be 'contagious'. Being contagious becomes an unexpected and negative identity marker.

Chapter 6

Social Networks and Identity

6.1 Introduction

This chapter focuses on the Pacific transnational community and the identity issues of Samoans growing up in New Zealand. The first part of the chapter examines social networks by firstly, analysing Pacific transnational communities and migration out of Pacific nations as well as internal migration within New Zealand. Social networks are important to Pacific migrants as they provide social support and pathways for disseminating information. Therefore it is necessary to examine social networks within the community with a particular focus on church contacts. Social networks however can also facilitate the outbreak of infectious disease. Using the interview transcripts, I examine if there were any such outbreaks as the result of social networks. The latter part of the chapter explores identity issues facing young Pacific peoples in New Zealand. This is followed by an analysis of the health beliefs of the younger participants in this study and how their family impacts on their health choices.

6.2 Social networks

A social network connects an individual with social contacts such as kin, neighbours and friends. Social networks are beneficial for those who have to adjust or cope with a major change in life, such as migrating or when faced with a serious health issue (Stansfeld, 1999). Social networks can also be detrimental to health as they can facilitate the outbreak of infectious disease (Klov Dahl et al, 2001). This is of major concern to Pacific peoples as they have many social networks that are not necessarily spatially concentrated. Further, the quality of contact with church groups and extended family is high, which means individuals frequently interact with these social networks. Going to church is not just a family matter, as seen with Leilani, who is

also involved with the Sunday school, mother's group and choir. Typically, Leilani interacts with her church contacts three times a week.

6.2.1 Transnational community

Of the 11 TB patients interviewed, only Luke and Leilani were born in New Zealand. Paul and Sina migrated to New Zealand in the 1960s and have been living in New Zealand for over 40 years. Like many of those who migrated to New Zealand during the 1950s and 1960s, Paul and Sina migrated to find better economic opportunities. Sina is a prime example of a transnational migrant. Over the last 40 years, Sina has travelled back and forth between New Zealand and Samoa regularly so that two of her four children were born in New Zealand and the other two in Samoa. Like other members of her generation, Sina raised her children in New Zealand, ensuring they got the best education as well as making the most of economic opportunities. Now that her children are adults themselves, Sina and her husband have chosen to return to Samoa to retire. Sina's migration pattern is not unusual to most Pacific peoples (see chapter 2). Pacific peoples leave their homeland at a young age to seek better education and employment opportunities and then return home to retire. From Sina's transnational point of view, she has suspended some traditional views in favour of western beliefs. For instance, she does not believe in *fofo* for herself but does believe that *fofo* can help others. Sina will only see western health professionals.

“And it does, ah, it does make people, you know, well again you know. Yes, many fofo's among our own people, yes they, I still believe that. But it's just that I just don't want it on me somehow, yeah. My mother and my father and everyone else of our family, they use fofo, and they're very very well. Some of them, they use the bible for it, and some of them use prayer, and some of them just use ordinary witchcraft which are quite good and useful for our people, and I like it to anyone else it's just that...personally I, I just don't feel that I would like to have it.”

Sina.

Mere has lived in New Zealand for 18 years. The rest of the participants migrated in either 1997 or 1998 except for Tara who was the most recent migrant, arriving in 2000. Tara was born in the Cook Islands but came to New Zealand as a toddler. So like many other Pacific peoples Tara had secondary and tertiary education in New Zealand after which she returned home to the Cook Islands. Tara decided to move

back to New Zealand because there were more opportunities as well as for family obligations. However, like the generation before her, such as that of Sina and Paul, she will eventually return home. As she explains

“...my poor house is sitting there all lonely you know, waiting for mummy to come home. But it’s something that I have been looking forward to, to going back and living there.”

Tara

Tara’s situation is very common to other Pacific peoples where they still have homes waiting for them in their homelands. Thus, they refer to both New Zealand and their island homelands as home.

Migrants are often seen as the cause for the increase of TB in New Zealand for which they are blamed for carrying the disease across New Zealand borders. Tara is the most recent migrant participant, having moved to New Zealand just over five years ago. While my study does not support the notion that migrants bring active TB into New Zealand, it finds that migrants seem to activate the disease more easily. This is supported by the research by Auckland Public Health staff in which, for the Samoan population in Auckland, most of those with active TB disease were infected in New Zealand (Thornley, 2005).

Leilani’s family is constantly accomodating family members who visit New Zealand. Leilani believes that these visitors are the source of her illness as she states,

“I think though, how I contracted it was because, um, they were always bringing people over from the islands and they were always here for like a long period of time.”

Leilani

Leilani’s statement alludes to just how transnational her family is with people frequently visiting from Samoa. She also makes a point that visitors often can bring disease with them. However, although visitors may have been the source of Leilani’s TB infection, it does not explain why or how her TB infection progressed into TB disease. Although a person may become infected with the TB bacillus it does not necessarily mean that they will get the actual disease. Of those who are infected,

according to the World Health Organisation (2005), only five to ten percent of people with TB infection progress into TB disease.

6.2.2 Social networks at work

Apart from the family, the other two most important social networks that participants used were their friends and their church. The most common theme that pervaded throughout participants' narratives is that those with a health culture of TB did not tell their friends or church members that they had the disease. This in spite of the fact their friends were often aware that they had health problems. When Tara was asked if anyone apart from her family and her friends knew that she has TB she responded,

"I don't tell them (friends) that I had TB um, they know that I have a community nurse that comes around. But they always ask questions, they go "Oh, is there anything wrong with you?" and I go, oh don't worry about it, its something that can be cured and and they go "ah, sweet." Yeah, 'cause it's embarrassing for me and I know I should tell them."

Tara

Sina also has a lot of friends whom she sees on a regular basis and plays cards with. She also has church members who visit her and help her because she is elderly and has health problems. But they have no idea that Sina has TB as she chooses not to tell them. The knowledge of her illness is kept strictly within the family. Reasons as to why this may be the case will be discussed later in the chapter.

As mentioned in the previous chapter, TB, for many participants has always been associated with marginalisation and death. It is not surprising, therefore that members of this group were somewhat guarded to share knowledge of their illness. Some participants had been reassured by the doctors that TB is no longer the disease they feared in the past, but despite this reassurance, some participants still refrain from informing friends about their situation. As Sina explains,

"Nobody knows, except my family...But they (doctors) said that it isn't like the TB that we used to have that was very contagious and very bad..."

Sina

Like Sina, Makelita believes that there is a duality to TB in which there is a Samoan TB and a New Zealand TB and that the later is not as bad as the former. This perception stems from their recent experience of TB in New Zealand which has been more positive as treatment for the disease is readily available and the disease, once identified, is curable. Also, the patients are reassured by doctors that the disease is the direct result of biological factors and this is always reiterated by the elderly Samoan participants when they are explaining what was the cause of their illness. Pepe, for example, exemplifies this in her narrative,

“...ave loa au i le falemai ma sue le toto ma mea faapena, ia ua iloa ua lavea au i le siama o le TB.”
Pepe

Translation: I was taken to the hospital and they did blood tests and things like that then it was known that I was afflicted with the TB germ.

For elderly Samoan participants interviewed, their past experience of TB was more ominous. For these people it was thought that once you had TB, certain death was near. Treatments at the time had not been successful, hence the association of TB with death. This was one reason why Makelita had real issues about her husband Paul coming home from hospital after isolation. Once Paul had been cleared of being infectious he was released to go home. However, the process was not simple because Makelita was absolutely opposed to Paul coming home. It took three doctors from Auckland hospital, as well as her GP, to convince her that Paul was no longer infectious and that it was safe for him to return home.

The cause of TB in the past for Samoans was more often not seen as biological but rather due to social factors. This is one explanation why TB is kept as a secret within the family, for most of the participants. Illness such as tuberculosis, in Tonga and Samoa especially (Ah Ching et al, 2001), was considered a consequence of either the patient or a family member having done a wrong in terms of cultural protocol and conduct or as a result of straining a relationship with another, whether it is another person, ancestor or God (Drozdow-St Christian, 2002; Macpherson and Macpherson, 1990). Although participants did not allude to this possibility directly, the narratives

on isolation in the past were always related to isolation within the family and not about isolation in the hospital wards. Sina reports that,

“...when you had TB in Samoa in those days, you’re isolated. You, you, your kept in a room on your own, everything is done is separately from you and all that...well, we (family) don’t sort of do any isolation or any special cup on your own, and your, and your dish, and your spoon, and your knife, no. I hate those kind of things.”

Sina

Isolation served two purposes. It prevented the disease from being spread, and as a means of distancing the person away from the family and trying to limit the damage done to the family’s reputation. Possibly, this is why Sione now lives alone, where as previously his sister and mother had been residing with him before it was known that he had TB.

From the foregoing discussion, a biomedical explanation is invariably regarded as better than the alternative. If biomedical reasoning for illness is a plausible cause, Pacific patients will tend to stress that it can be nothing else but biomedical. Sina’s narrative illustrates the emphasis put on doctor’s biomedical information and explanation,

“...that’s how they (doctors) said some, that TB germs can live, can be within a person for all his life and not knowing until something happens and it triggered that to come to the front of things, that brings it to, that comes out to be TB so I just go along with it, information from the doctors and their instructions.”

Sina

For many Samoans, illness is inherently the result of social causes. Samoans may try to hide the fact that they are ill in order to avoid accusation and suspicion on their family. Therefore western medical clinics become a haven because of the secrecy and privacy of treatment. For Samoans, the dignity and honour of the family is paramount and safeguarding and protecting the family’s reputation from any social disrepute can sometimes supersede treatment as a priority (Drozdow-St Christian, 2002).

Leilani's mother's denial of her daughter's illness may also be associated with the fear surrounding the social repercussions of having TB as this dialogue explains,

Leilani: Yeah, ah, my island side there, they were like going, kept telling me to go down and see my grandmother and that. And that it's not TB, its just, um, it's something just, lumpy. She didn't believe that it was TB.

Roannie: Aha, and what did you tell her?

Leilani: I kept telling her and she didn't believe me when I kept, I showed her like this... 'cause I got a scar and that. I showed her my medication and she didn't believe me.

Later, when asked why her mother didn't think it was TB, Leilani said she did not know. Her mother never told her why she thought it was not TB but insisted that it just could not be the disease. This puts into perspective what Elisapeta commented on about Samoan attitudes toward TB and the 'not in my backyard' syndrome which sees TB as only affecting others:

"I, I feel sorry for them (TB patients) but at the same time I'm glad it's happen to them and not in my family."

Elisapeta

Causation of illness for Pacific peoples is never really as straightforward as the biomedical perspective surmises. However, encouraging participants to talk about causation is just as complex. Participants may not want to share or admit that something other than biomedical agents caused TB. For Pacific people, causation of illness is also highly politicised, which is why the knowledge of TB for most of my participants is always kept in the family and never shared with others.

There were a few participants who had no qualms over sharing knowledge of their illness with others outside of their family. This is especially interesting since Tuvalu has a significantly high TB rate. However, TB incidence may be related to the main island of Funafiti, rather than the other smaller islands, which is where Sarah and her family originally came from. Sarah and her family had heard through nurses that TB was 'scary' but after the doctors explained that the disease is easily curable they no longer feared the disease. Consequently they had no reservations in informing their

friends and their church members that they were ill with TB when the situation emerged.

Mere, an elderly Cook Island woman has many friends who are part of her congregation and who also know that she has TB. Before becoming ill with TB neither her nor her family had heard of the disease, or could think of how she contracted it. Thus, because they viewed it as akin to pneumonia which she also suffered, TB was seen as just like any other illness that can be treated. What is comforting for Mere is that her friends often visit and have a prayer meeting which comforts her and leaves her in high spirits. This illustrates Stansfeld's (1999) argument that quality social support from social networks can facilitate well being. It is unfortunate that not a lot of the other participants share this experience.

There are some cases where the disclosure of a patient's TB condition is unavoidable. Petelo, for instance, had been ill for such a long period that over time a lot of other people became aware that he had a health problem. This mainly arose because Petelo had been to see a *fofo*. As with most Samoan families, when a family member becomes ill, it becomes a family affair (Tukuitonga, 1990) and so as different family members inquire into finding the right *fofo* for treatment a larger group of people become involved as Petelo illustrates,

"...you know, Samoan family, so I mean we're tight and all that. In a way, when someone's as ill as I am, you know, everybody's concerned."

Petelo

Family concerns for Petelo meant that once he was diagnosed, a large group of people found out that he had TB as people wanted to assist to find a *fofo* to cure his ailment. This is common as Samoans always like to know which *fofo* was successful in treating certain symptoms for future reference. However, Petelo expressed that he would have preferred for his illness to be kept within the family,

"Oh yeah, yeah, the whole community (knows)...if I had a choice too I wouldn't let anyone know, but it's just that, in my case, people had known that I'd been ill, so can't really help that one."

Petelo

For all my study participants, families were their main source of comfort. They provided much needed support emotionally, as the treatment can be difficult because of the commitment required in terms of the length of time for treatment. Further, there is a large amount of medication that should be taken. For example, Tara's treatment required a total number of 18 pills. During Tara's time in isolation at hospital, her family provided the emotional and mental support to help her during this difficult period in her illness.

"If I didn't have anybody to sit down and talk to I would, I'd probably go bonkers in here. Honestly, I would have just felt sorry for my fricken self and just whittle away type of thing...they tried to comfort me the best way they knew how."

Tara

6.3 Households and outbreaks

Internal migration and housing play a significant part in the spread of TB and outbreaks. Pacific people move quite frequently within New Zealand (Ministry of Health, 2005). They often visit other family members across New Zealand for lengthy periods of time, especially when they first migrate to New Zealand to find the best location and employment opportunities that suit their needs (Macpherson, 2004). The transmission of TB then becomes more complex as the geographical distribution can widen with the movement of a single individual. Tara had stayed with family in Wellington where contact tracing established that is where she caught the germ. She then moved to Auckland and was unaware that she was infectious. The household that she moved into in Auckland then increased to 10 individuals with four adults and six children living in a three bedroom home. Tara's household composition reflects a common plight for many Pacific peoples especially for health reasons, as previous studies examining health and welfare implications have indicated (Cheer et al, 2002).

Overcrowding has long been established as a concern for Pacific peoples (Milne and Kearns, 1999) and a major factor in the spread of disease for my participants. Four of my participants were living in what they considered to be crowded conditions and all four participants eventually infected children living in their households. Luisa lives in Samoa with her children and her great grandchildren. Four of her grandchildren had to be treated for TB infection. Mere's primary caregivers are her family and so her

household included her children and her grandchildren. Mere's illness unfortunately led to two of her grandchildren also being infected and needing treatment. Since the family has learnt of the disease and how it is spread, Mere's household has now reduced in size to four.

Mataeo also lives in overcrowded conditions where he shares a three bedroom house with four other adults and five children. Three of the children became infected with TB and are being treated for TB infection. Mataeo's household is an example of how easy it is to transmit TB from one household to another. Mataeo's extended family live at another address in a nearby suburb. This household is similar to Mataeo's where there is overcrowding and which has led to the spread of the disease within the household. What has proven to be a challenge for the Auckland public health service in terms of contact tracing is that members of both households frequently move between the two addresses so that it is difficult to know who exactly lives where. Although this poses a problem for the public health service and especially for the nurses administering DOT, these arrangements are only natural for this Tuvaluan family. As seen in the Pacific, the household as an entity, as it is known in New Zealand, is different to that in the Pacific. In Samoa one household would include many homes belonging to the family no matter where the location.

6.4 Identity

6.4.1 Identity for New Zealand- born Pacific peoples

Two participants in my study were born in New Zealand. However, their upbringing is entirely different. Leilani who is 28 years old has never been to Samoa; although she is very fluent in the Samoan language. She was raised within the church and her parents were very strict in administering their policy of English being limited to within school grounds. Although Leilani has never been to Samoa she is well-versed in the *fa'asamoa*, something in which the church has played a vital role in Samoan people's ethnic identity. One concept that Leilani has not adapted to entirely, however, is traditional medicine and *fofo* as I have pointed out in the previous chapter. Leilani feels strongly that western medicine is a lot more advanced and much better than Samoan medicine.

Luke, on the other hand, does not attend church regularly and has been to Samoa a couple of times but cannot speak Samoan. This, however does not faze him as he pronounces quite nonchalantly,

*“I can’t speak Samoan but I don’t have any identity issues or anything.
I’m still Samoan.”*

Luke

Identity for young Pacific peoples in New Zealand varies as insights from my second focus group reveals. Of the two New Zealand-born participants, only Leonie identified as a New Zealand born Samoan. The other, Marcus, identified himself as Samoan. Leonie called herself a New Zealand-born Samoan because like Luke, she too cannot speak Samoan although she can understand it. She is very proud of her Samoan background and has a basic grasp of *fa’asamoa* that was instilled through her grandparents. Leonie’s parents, who are also New Zealand-born, are in their early 40s, a generation that was brought up at a time when speaking Samoan in New Zealand was discouraged, an issue that I have already discussed in Chapter 2.

Marcus’s upbringing was somewhat different as he, like Leilani, had been brought up with *fa’asamoa*, attending church regularly and can speak Samoan fluently. Marcus solely identifies himself as a young Samoan and has no struggles with identity issues when in New Zealand, or Samoa. Marcus’ parents are a generation older than Leonie’s and migrated to New Zealand as young adults. Thus, for Marcus *fa’asamoa* is the typical way of life in his household.

The other two participants, Pati and Susana were born and raised in Samoa and so identify themselves as Samoans. Because of the large Samoan community already in Auckland, the transition to Auckland life has not been so difficult. Adjusting or trying to fit in at school was not a real issue as many of the students in their schools spoke Samoan in the playground.

6.4.2 Health choices for young New Zealand- born Pacific people

As I have stated earlier in this chapter, health seeking behaviour is a family affair and parents as well as elders of the family determine the course of action to take when a child becomes ill. For my young focus group participants it was not uncommon, as young babies, to be taken to consult a *fofo* first, rather than seeing a doctor. Even now, as young teenagers and adults the pathway of treatment still lies with the parents and grandparents. As Marcus notes,

“Yeah I always go see the fofo, my aunty first, cause of my parents and then if I don’t get any better then I go see the doctor.”

Marcus

All the focus group participants have current access to traditional healers and have used them at least once. Marcus, along with Leonie, prefers to consult only his GP. Marcus finds that his lack of control in the decision-making process on who to consult regarding his health is sometimes frustrating. He believes that most of visits to the *fofo* were a “waste of time”. Pati and Susana have other ideas as to where they would prefer, to see the *fofo*, and would only visit their GP as a last resort. They believe that as Samoans, Samoan medicine is best for them.

One interesting aspect that arose from my interview with Luke, was his belief and attitude toward traditional medicine. If he had access to a traditional healer he would definitely consult them. As Luke explains,

“Well only from what I’ve heard of the traditional ways, you know, a fofo and that work...so I’d rather do that than see a doctor, but I’m not going to have access to anyone who knows how to do that.”

Luke

Luke’s mother does not personally believe in Samoan medicine either, although she was raised in Samoa. This is because her past experience with Samoan medicine had not been pleasant or successful. Therefore, when raising her children in New Zealand, traditional medicine was never considered or talked about in the family.

6.5 Conclusion

Pacific peoples are transnational migrants and the situations of participants in this study do not support the idea that migrants bring TB into New Zealand. The reality is that TB disease does not appear to affect the migrants until they have been well-established in New Zealand. The issue is not that migrants bring the disease in to New Zealand; rather it is a question of what are the causes that make Pacific peoples more likely to activate TB disease. The high TB rates in Pacific nations, however, do increase the possibility of people becoming infected with TB. The utilisation of social networks in relation to TB participants is dependent on the participants' belief and past experiences with the disease. The participants who had preconceived negative ideas about TB before becoming ill were less inclined to disclose their health problems to people other than their families. This observation is also linked to beliefs about the causation of illness as Macpherson and Macpherson (1990) have outlined, whereby TB may be the consequence of a social transgression. This, in turn, may taint the reputation of the family affected by TB and therefore marginalise the patient even more. Therefore, nurses become important substitutes for social networks in terms of providing emotional support and helping patients to cope with, and adjust to, the illness. Young Pacific people growing up in New Zealand often face identity challenges. These identity issues are further related to their cultural beliefs and how they have been raised. The young Pacific participants in my study illustrate how growing up in New Zealand as a Pacific person has meant that their health experiences involve a combination of both traditional and western biomedical perception and practices. The implications of these features are discussed in the conclusion chapter.

Chapter 7

Conclusion

7.1 Conclusion

This thesis has examined the relationship between Pacific peoples and tuberculosis in Auckland and Samoa. The thesis is more concerned with ascertaining the social determinants of TB, hence the political ecology approach in examining the epidemiology of the disease. The high rates of TB for Pacific Peoples in Auckland, is a matter of concern for public health and the populations themselves. Because the rates of TB are higher in the Pacific Island nations, Pacific migrants have a greater opportunity to become infected. However, infection is necessary, but not sufficient, for the progression of disease and the fact that many migrants experience TB long after settling in New Zealand means Pacific migrants are not bringing active TB into New Zealand. Therefore understanding why there are high rates of TB for Pacific peoples in Auckland is critical. To investigate and shed some light on this matter, this thesis has examined Pacific cultural identity and how this has impacted on Pacific people's sense of place within Auckland, how identity influences health beliefs, and in turn, how these beliefs impact on the health seeking behaviour of Pacific TB patients and how social networks are utilised.

Cultural identity informs our explanatory models and encroaches on how we perceive things and how we behave. Thus, as migrants in Auckland, Pacific peoples bring with them their own ideas of health and healing and instead of adapting to, or adopting western health beliefs and institutions straight away, some tend to continue their traditional practices and way of living. Pacific peoples view health as a social phenomenon rather than strictly a biological concern. The TB patient interviews support this assertion. Because illness is viewed as a social construct the cause of illness is often thought of as social. As outlined in Chapter 3, Samoans view illness as

the result of a social disruption in which some social code or custom has been transgressed.

Therefore seeking treatment and healing methods becomes a complicated issue whereby biomedicine and western treatment is not always considered and can explain why Pacific peoples delay seeking medical attention as soon as illness symptoms arise. Thus for Pacific peoples in Auckland, their landscape of health care is inherently different to Pakeha. In terms of surveillance and controlling TB and other diseases, this becomes a problem for public health professionals as there are no formal facilities of traditional healing. Therefore, it becomes difficult to monitor the health of Pacific peoples who choose to use traditional healers instead of western alternatives.

Some of the study participants who migrated to New Zealand in the 1990s still prefer traditional healers over doctors, mainly because of language barriers and they would have been uncomfortable with doctors who probably could not relate to them, nor understand their Pacific worldview. They also had difficulty accessing western health care whereas, through social networks, it was easier to find healers. Although there are specific Pacific primary healthcare organisations available now, for some, their location means that these health services are not easily accessible, especially when transport is an issue. A few of the participants spoke of becoming sick for awhile but attributed this to the stresses of migration and adapting to the cold environment and therefore did not appreciate the seriousness of their condition.

Another pertinent health and migration issue is housing. Many migrants come to New Zealand before establishing what accommodation they will occupy. Often, migrants stay with families until they are able to find their own accommodations. This means that they may live in overcrowded housing conditions which are not conducive to healthy living. This tendency, coupled with the stresses in adapting to a new environment which is completely different to their island homeland, can precipitate ill health. Three of the study participants living in New Zealand, had infected others as a result of overcrowding. Overcrowding is, however, not solely a migration outcome or a consequence of financial hardship but is also seen as a result of social support. Two participants who were living in overcrowded conditions changed their living

arrangements once it was known that they had infected others with TB. Migration therefore can be viewed as a social stressor that can activate TB.

Half of the Pacific migrants that were interviewed have been living in New Zealand for well over 10 years. The most recent migrant in this study migrated permanently five years ago, but had been living periodically in New Zealand for educational reasons. This thesis does not support the assertion that migrants are bringing active TB to New Zealand, but rather that they are the most susceptible group in activating TB disease.

For Pacific peoples in Auckland, health culture is extremely important for TB. For example, the Samoan participants I interviewed stressed how stigmatised TB was, because it was infectious and deemed incurable. They also recounted the attitudes that the general population had towards TB patients in situations where patients were isolated and marginalised. The practices used in a TB control program implemented by the US Naval Medical Team in American Samoa further legitimised the fear of the disease where isolation was mandatory by law. This further fuelled Samoans' beliefs about TB, believing that if a powerful institution such as the US Navy is taking such aggressive measures and actions, then it must be bad. It was not uncommon for TB patients in Samoa to be isolated from and by their family. This was both because of biomedical and social concerns whereby families of TB patients feared negative publicity on their family's reputation from having a family member afflicted by the disease.

Samoan participants living in New Zealand surmised that there appears to be a duality to TB which is related to their experience of the disease in New Zealand and Samoa. They believe that there is a Samoan TB and a New Zealand TB. They categorise Samoan TB as being the disease that is incurable while the New Zealand TB is curable. This is an important deduction for Pacific TB patients, given that the thought of having TB is an inevitable sign of death can be seriously detrimental to the patient's mental health. This is important in re-educating people on the nature of TB and clearly stating that, once caught TB, is an easily curable disease providing there are no other serious health issues (and even with these it is still curable).

Social networks play an important and integral part of life, especially for Pacific peoples. Thus the most surprising result from this study is the under-utilisation of social networks in order to cope with and manage TB. This tendency can, in part, be explained by the TB health culture in the Pacific as well as the holistic worldview of Pacific peoples where illness, especially one as stigmatised as TB, is viewed as a consequence of the family or patient behaving inappropriately and contravening a social belief. From the participant interviews it is evident that those with a stigmatised health culture of TB strictly kept the knowledge of the illness within the immediate family. This, therefore, can explain that while participants were still actively utilising their social networks such as the church and their friends on a regular basis, these contacts were oblivious to the participant's condition.

For those who had no health culture regarding TB or did not view TB as a stigmatised disease, their social networks became an integral part of their healing process. This strengthens the arguments for social networks being conducive to well being. For participants who utilised these networks, they provided much-needed emotional support. In much the same way, the public health nurses administering treatment for TB provided much-needed emotional support for those who did not utilise their social networks.

From this thesis it is evident that much work needs to be done in re-educating Pacific people about TB. Although it is a disease that is well known within the general public through BCG vaccinations, and media discourse of late surrounding TB and migration, what is now known about TB is different to what was available in the past, and this information should be more readily available to the general public. Further, as seen with Samoa's campaign on tuberculosis, re-education has changed attitudes surrounding TB. Patients there are no longer ashamed or fear having the disease which can be conducive to treatment compliance as well as improving patients' mental health.

The importance and significance of educating Pacific people must not be underestimated as it can help eliminate the stigma of TB. This, in turn, can lead to people utilising their social networks more effectively in coping with the illness and

facilitating well being. This is especially important in relation to TB where the course of treatment is lengthy.

Further, for patients in isolation the experience is one of loneliness and frustration as freedoms are limited. Although much cannot be done about keeping patients in isolation and having to wear masks, doctors must be aware of the sensitivities of patients when speaking in medical terms. Also, when in isolation patients have few options to keep themselves entertained which makes the term of stay even more unbearable as they have more time to contemplate their situation. Thus, activities should also be made available to patients such as arts and crafts which can help them to remain busy and focus on other things for a time at least.

For migrants more needs to be done in terms of accessing healthcare providers as well as stressing the importance of seeking medical advice once they become ill. Thus in the settlement packets and information provided for new migrants, it must expressly be stated that there are Pacific primary health organisations and where these are situated. This will assist with the problems of migrants delaying seeking medical attention with dire consequences.

More research needs to be conducted as to why Pacific peoples delay seeking medical attention. While my study shows that Pacific healers actively refer patients with some medical problems to GPs or hospitals, it seems likely that many medical practitioners are unaware of the extensive use of Pacific healers amongst their patients. Furthermore, surveys need to be done to find out how many Pacific peoples do use traditional medicine as I believe the Ministry of Health's estimate of 3.3% is incorrect. Discovering the reasons for the delay provides an opportunity to determine solutions and therefore leads to early detection as well as preventing the spread of TB.

Placing the experience of TB firmly within the everyday lives and geographies of Pacific peoples, as this thesis has done, is an important step towards a more complete understanding of the links between health, disease and society in contemporary New Zealand and the Pacific.

APPENDICES

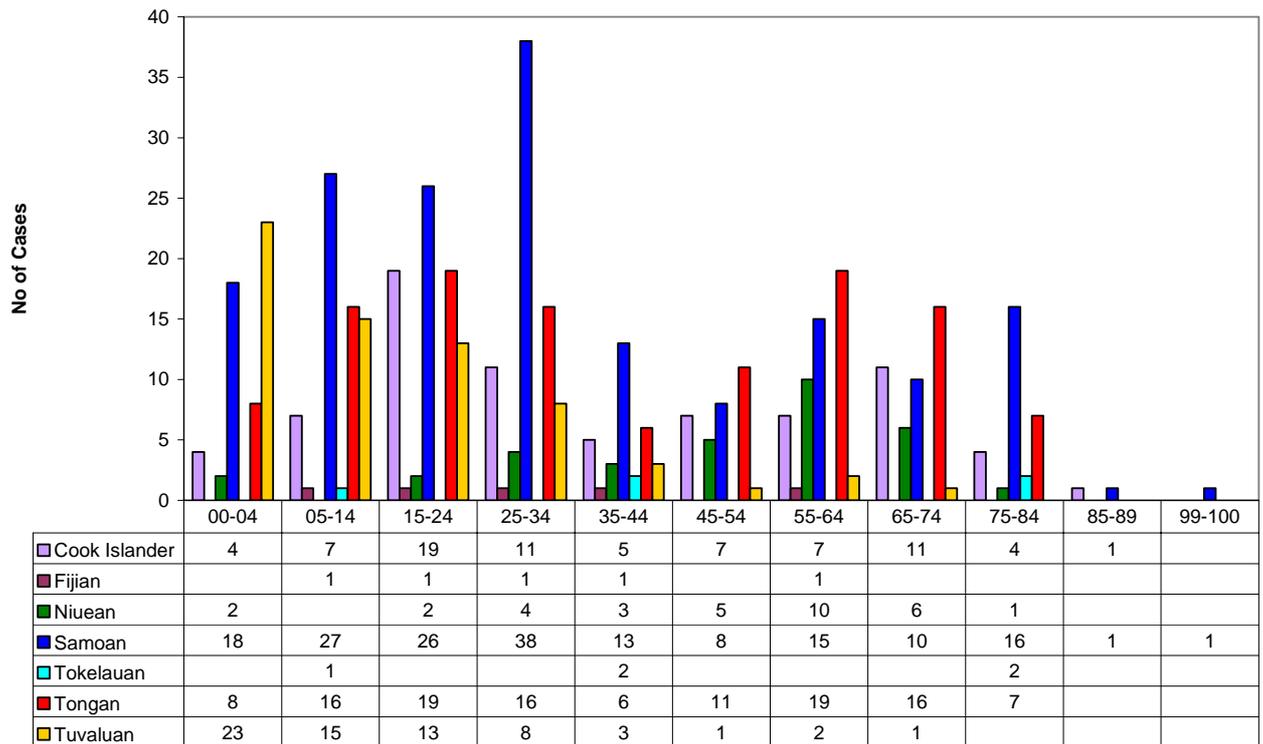
Appendix 1: **Graph of Pacific TB cases in Auckland from 1995-2005 by age group and ethnicity.**

Appendix 2: **Consent Forms**

Appendix 3: **Participant Information Sheets**

APPENDIX 1

Pacific TB cases in Auckland from 1995-2005 by age group and ethnicity



Source, Thornley, 2006.

APPENDIX 2

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Consent Form for Samoan Medical Professionals

This Consent Form will be held for a period of six years.

Project Title: The Political Ecology of Tuberculosis in Samoa

Researcher: Roannie Ng Shiu

I have been given and have understood an explanation of this research project. I have had an opportunity to ask questions and have them answered. I understand that my participation in this study is strictly voluntary.

I understand that I may be recorded and that I may obtain a copy of the tape if I wish. As well, I understand that in drawing on my account for publication purposes no names or identifying details will be used.

All material collected will be held in a locked filing cabinet, and after 6 years, these research materials will be destroyed (paper shredded and tapes destroyed).

- I agree to take part in this research.
- I agree to have my interview audio taped.
- I may withdraw myself, or any information traceable to me, at any time within three months of this interview, without giving a reason.

Signed: _____

Name: _____
(*please print clearly*)

Date: _____

**APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 24/02/05 FOR 3 YEARS
REFERENCE NUMBER 2005 /071**

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Consent Form for Samoans with Experience of TB

This Consent Form will be held for a period of six years.

Project Title: The Political Ecology of Tuberculosis in Samoa

Researcher: Roannie Ng Shiu

I have been given and have understood an explanation of this research project. I have had an opportunity to ask questions and have them answered. I understand that my participation in this study is strictly voluntary.

I understand that I may be recorded and that I may obtain a copy of the tape if I wish. As well, I understand that in drawing on my account for publication purposes no names or identifying details will be used.

All material collected will be held in a locked filing cabinet, and after 6 years, these research materials will be destroyed (paper shredded and tapes destroyed).

- I agree to take part in this research.
- I agree to have my interview audio taped.
- I may withdraw myself, or any information traceable to me, at any time within three months of this interview, without giving a reason.

Signed: _____

Name: _____
(*please print clearly*)

Date: _____

**APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 24/02/05 FOR 3 YEARS
REFERENCE NUMBER 2005 / 071**



Consent Form for New Zealanders experience of TB

This Consent Form will be held for a period of six years.

Project Title: The Political Ecology of Tuberculosis in Auckland and Samoa

Researcher: Roannie Ng Shiu

I have been given and have understood an explanation of this research project. I have had an opportunity to ask questions and have them answered. I understand that my participation in this study is strictly voluntary.

I understand that I may be recorded and that I may obtain a copy of the tape if I wish. As well, I understand that in drawing on my account for publication purposes no names or identifying details will be used.

All material collected will be held in a locked filing cabinet, and after 6 years, these research materials will be destroyed (paper shredded and tapes destroyed).

- I agree to take part in this research.
- I agree to have my interview audio taped.
- I may withdraw myself, or any information traceable to me, at any time within three months of this interview, without giving a reason.

Signed: _____

Name: _____
(*please print clearly*)

Date: _____

**APPROVED BY THE AUCKLAND ETHICS COMMITTEE REFERENCE
AKX/03/01/003**



O le Faamaumaiga o lo'u ioeina

E teu le pepa lea mo le ono masina

Mataupu: Iloiloina O le mataupu e faatatau I tagata ua maua le fa'amai o Tuberculosis (TB)

O le Tagata Suesue: Roannie Ng Shiu

O lenei su'esu'ega ua uma ona fa'amalamalamaina mai ia te a'u, ma ua ou malamalama foi iai. Sa maua le avanoa mo ni a'u fesili ma ua fa'amalieina foi I tali ua tuuina mai.

O lo'u au ai I lenei su'esu'ega, ua faia lava lea I lo'u lava loto malie.

Ua ou iloaina o lenei su'esu'ega e mafia ona faa'aogaina tusitusiga po'o laau pu'e leo, ma, e mafia ona tu'uina mai ia te a'u se kopi I so'o se taimi ou te manao I ai.

E matua'I fa'asaina ona lomua lo'u igoa po'o lo'u nei tagata I so'o se auala ini fa'asalalauga o lenei su'esu'ega.

O tusitusiga uma po'o lipine o lenei su'esu'ega, e tataua ona teuina ma loka lelei I se nofoaga mautu, ma a, uma le ono tausaga ona fa'atamaia uma lea, e ala lea I le faaleagaina o lipine, susunu pe oti nini pepa.

Ma

- Ua ou ioeina lo'u auai I lenei su'esu'ega
- Ua ou ioeina fo'I le fa'aogaina o laau pu'e leo
- E mafia foi ona ou talosagaina, e aveeseina mai tua faamaumaiga uma o lo'u auai I lenei su'esue'ga I totonu o le tolu masina mai le aso o ole su'esu'ega, e aunoa mase fesiligia ole mafuaga

Saini: _____

Igoa: _____

Aso: _____

Faatagaina e le Iunvesite o Aukilani Human Participants Ethics Komiti I le 17 Mati 2005 mo le tolu tausaga. Reference 2005/071.

APPENDIX 3

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PARTICIPANT INFORMATION SHEET

Project Title: The Political Ecology of Tuberculosis in Auckland and Samoa

To: Auckland resident with experience of TB

My name is Roannie Ng Shiu. I am a Masters student in Geography at the University of Auckland, where I am part of a team of social researchers studying aspects of the experience of tuberculosis (TB). My part of the study is considering the experience of TB for Samoan people both in Auckland and here in Samoa.

The aim of the study is to find out about the successful treatment and prevention of TB as well as the lived experience for those diagnosed with TB and their families. The research is designed to benefit people with TB and their communities and those who care for them by producing information that can be used in service provision, the provision of support, lobbying for resources and in educating both those with TB and those in wider society about TB.

I am interviewing people who have had TB in the past and at present, people who have had TB patients in their families or among their friends, health professionals who work in the area.

As part of my study, I would like to speak with you in your capacity as someone who has experience of TB. You are invited to participate in my research and I would appreciate any assistance you can offer me, but you are under no obligation at all to take part in the study.

If you are agreeable, I would like to take about 30 minutes of your time to interview you about your perceptions and experience of TB. The study will take place in various venues in Auckland. The time span for this study is one year. Your participation is entirely voluntary.

The interviews will be audio-taped with your permission. Tapes will be destroyed on the conclusion of the study. Where tapes are transcribed, transcripts will also be archived with the participants' permission. Transcripts will be destroyed after six years.

If you agree to take part in this research you are free to withdraw from the study within three months of the interview, without having to give a reason. During the interview you do not have to answer all the questions, and you may stop the interview at any time.

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.

Outputs of the study will include my Masters thesis and at least one academic journal publication. I will be glad to supply a summary of the completed study on request in early 2006.

Thank you very much for your time and help in making this research possible. You may withdraw yourself or any information traceable to you at any time up to three months after the interview without giving a reason.

You can contact me directly to seek further information about this study .My email address is rngs001@ec.auckland.ac.nz. My supervisor is Associate Professor Robin Kearns. His email address is: r.kearns@auckland.ac.nz

My Head of School is: Dr Willie Smith

School of Geography & Environmental Science

University of Auckland

Private Bag 92019

Auckland.

For any queries regarding ethical concerns please contact: The Chair, The University of Auckland Participants Ethics Committee, The University of Auckland, research Office - Office of the Vice Chancellor, Private Bag 92019, Auckland. Tel: 373-7999 extn 87830.

Approved by the Auckland Ethics Committee Reference AKX/03/01/003

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PARTICIPANT INFORMATION SHEET

Project Title: The Political Ecology of Tuberculosis in Samoa

To: Samoan resident with experience of TB

My name is Roannie Ng Shiu. I am a Masters student in Geography at the University of Auckland, where I am part of a team of social researchers studying aspects of the experience of tuberculosis (TB). in Samoa. My part of the study is considering the experience of TB for Samoan people both in Auckland and here in Samoa.

The aim of the study is to find out about the successful treatment and prevention of TB as well as the lived experience for those diagnosed with TB and their families. The research is designed to benefit people with TB and their communities and those who care for them by producing information that can be used in service provision, the provision of support, lobbying for resources and in educating both those with TB and those in wider society about TB.

I am interviewing people who have had TB in the past and at present, people who have had TB patients in their families or among their friends, health professionals who work in the area.

As part of my study, I would like to speak with you in your capacity as someone who has experience of TB in Samoa. You are invited to participate in my research and I would appreciate any assistance you can offer me, but you are under no obligation at all to take part in the study.

If you are agreeable, I would like to take about 30 minutes of your time to interview you about your perceptions and experience of TB in Samoa. The study will take place in various venues in Upolu. While the time span for this study is one year, I am only in Samoa undertaking research for two weeks. Your participation is entirely voluntary.

The interviews will be audio-taped with your permission. Tapes will be destroyed on the conclusion of the study. Where tapes are transcribed, transcripts will also be archived with the participants' permission. Transcripts will be destroyed after six years.

If you agree to take part in this research you are free to withdraw from the study within three months of the interview, without having to give a reason. During the interview

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

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.

Outputs of the study will include my Masters thesis and at least one academic journal publication. I will be glad to supply a summary of the completed study on request in early 2006.

Thank you very much for your time and help in making this research possible. You may withdraw yourself or any information traceable to you at any time up to three months after the interview without giving a reason.

You can contact me directly to seek further information about this study .My email address is rngs001@ec.auckland.ac.nz. My supervisor is Associate Professor Robin Kearns. His email address is: r.kearns@auckland.ac.nz

My Head of School is: Dr Willie Smith

School of Geography & Environmental Science

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Private Bag 92019

Auckland.

For any queries regarding ethical concerns please contact: The Chair, The University of Auckland Participants Ethics Committee, The University of Auckland, research Office - Office of the Vice Chancellor, Private Bag 92019, Auckland. Tel: 373-7999 extn 87830.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 17 March 2005 for a period of 3 years. Reference 2005/071

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Faamatalaga e faatatau I le su'esu'ega

Talofa lava

O a'u o Roannie Ng Shiu mai le Iunivesite o Aukilani I Niu Sila. O se tasi o le au suesue o loo iloiloia le mataupu e faatatau I tagata ua maua I le fa'amai o Tuberculosis po'o le TB.

E valaauina ma le faaaloalo sau feasosoani mo lenei sailiga, auala atu I lou auai I le faatalanoaina o lenei mataupu.

O ni finagalo o le a faalia ma ofoina mai mo lenei talanoaga o le a teu malu e le faailoaina faalauaitele. E le faamalosia foi lau auai pe a le tusa ai ma lou finagalo, ma e pule lava oe pe e te le fia tali I soo se fesili o le a faatalanoaina.

Ina ia mautinoa e tonu ma sa'o le faamaumauina e finagalo o le a folasia I lenei talanoaga I se talosagaina ai sou maliega e pu'e ai se la'au pu'eleo (tape recorder) ia lenei talanoaga.

E mafia foi ona e talosagaina, e aveeseina mai tua faamaumauga uma o lo'u auai I lenei su'esue'ga I totonu o le tolu masina mai le aso o ole su'esu'ega, e aunoa mase fesiligia ole mafuaga

O nisi o loo faauluulu iai le sailiga e aofia ai:

Dr Robin Kearns
School of Environmental Science and Geography
The University of Auckland
Private Bag 92019
Auckland, New Zealand

Dr Julie Park
Anthropology Department
The University of Auckland
Private Bag 92019
Auckland, New Zealand

O le a faailoa faalauaitele I le lipoti o lenei sailiga I se lipoti o le a tuuina atu I le Matagaluega o le Soifua Maloloina.

Afai e te toe fia maua au a ua uma na fai le talanoaga o lo'u email o rngs001@ec.auckland.ac.nz. O le e-mail o lo'o supervisor foi o r.kearns@auckland.ac.nz.

Faatagaina e el Komiti e puipuia le Sologa manuia Tagata Lauetele mai Suesuega Faasienisi a le Iunivesite o Auckilani (The Chair, The University of Auckland Participants Ethics Committee, The University of Auckland, research Office - Office of the Vice Chancellor, Private Bag 92019, Auckland. Tel: 373-7999 extn 87830.) O le reference 2005/071.

Fa'afetai lava mo lou feasosoani

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