

**HAVING TB:
THE EXPERIENCE OF PĀKEHĀ IN AUCKLAND**

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A thesis submitted in partial fulfilment of the requirements for a the degree of Masters of
Arts in Anthropology, University of Auckland, 2004

ABSTRACT

As tuberculosis has been a treatable disease for the past 50 years it is astounding that it continues to affect one third of the world's population. In New Zealand there has been an increased incidence of TB disease since 1988.

This study is concerned with the meaning of tuberculosis for Pakeha with TB in New Zealand. This research is a component of a larger study, *The Political Ecology of TB in New Zealand* of TB in five ethnic groups in Auckland and of the history of TB in New Zealand since 1940.

Although Pakeha are the largest ethnic group in New Zealand, they have the lowest incidence of TB, which affects mainly the elderly. Through the use of participant observation and semi-structured interviews of Pakeha in Auckland with TB disease I interpret their experiences of the early stages of disease, diagnosis and treatment in the context of their daily lives. As people interpret illness through a lens of previously held conceptions of health, I extended my research to include a focus on the health and illness attitudes of 'well' participants of similar status to the TB sufferers. Through my analysis of fieldnotes and interviews I identified several themes relating to the experience and understanding of TB, and health more generally.

I contest that Pakeha experience TB and associated stigma that it still carries in the context of a community that knows little about TB and it is conceived as a disease of the 'unhealthy other'. As a comparatively rare disease for Pakeha, the association of migrants with TB causes Pakeha TB to be invisible. When the disease does arise it can consequently be subject to delays in diagnosis and an upheaval for the sufferer in accepting a disease that they attribute to the 'other'. Elderly people with TB have specific difficulties with diagnosis and treatment. Several participants were experiencing TB for the second time around, giving insight into the great changes in the management of TB that have occurred between episodes of their disease. Care throughout the treatment process was crucial to the adherence to treatment by participants of all ages. The social and emotional component of care I have identified as of particular importance to supporting the lengthy and difficult

treatment required by TB disease. Despite this, there was a disparity between the hope for outcomes of treatment by patients and clinicians. Whereas a cure aimed for elimination of the infection, clients wished for a return to their pre-TB health status.

Keywords:

ACKNOWLEDGMENTS

I am indebted to the Health Research Council for the scholarship they granted as part of *The Political Ecology of TB* project of which this thesis is part. The TB project also received a University of Auckland Committee grant has funded a research assistant (Deanna) for the TB project who has been a help to us all. I am also appreciative for the valuable opportunity I was offered to be a part of a multi disciplinary project that has provided me with support , encouragement and the opportunity to meaningfully ‘talk TB.’

I took great pleasure in spending time with participants who have made the study possible by sharing their stories about life with TB. I am grateful to each of you. I would not have met my participants without the commitment that the Public Health Nurses made to my research and the TB study as a whole. They took care to ensure that they contacted all of their eligible clients and offered cheerful advice when I needed it. Dr. Craig Thorely also shared his expert knowledge about TB with us as students of the TB Project, in a ‘TB101’ teaching session. He also gave valuable assistance with sourcing local data. Thanks also to the management of the TB Association, TB ward and clinic who gave their time to explain their work.

The writing process was fraught with huge emotional fluctuations, marked by moments of despair and excitement when new ideas ‘dropped in’. I have made it through these challenges with practical help and support from my supervisors and colleagues in the Anthropology department and I thank you all.

I am enormously indebted to my supervisors, Julie Park and Judith Littleton for their enduring support through the struggle. At times when my spirits flagged they pulled me through the ‘muddy bits’. I have huge respect for their academic acumen and their roles as outstanding supervisors and this has encouraged me in reaching my goal.

Fellow students have been fun and wonderful moral support. I am particularly grateful to Jodie, Anneka, Debbie and Deanna in the TB project, also Tim, Nigel and Andrew for technical help. Donna, Jodie and Anne offered ongoing cheer and help with editing and smoothed the challenges of computer technology as I learned as I went. I appreciated the moral support and camaraderie that staff and students of anthropology gave

freely. Thanks also to my room-mate Tony for putting up with the mess! I enjoyed yarns with Helen, David, Sally, Maked, Christina, Jeanette and Sarah and Tony and they were light relief along the way. Thankyou all!

Finally I am deeply grateful to my family, to Des, Tom, Joy, Will, Oscar and Hazel for believing I could do it, for their love and support that often meant getting along without me.

TABLE OF CONTENTS

ABSTRACT	1
ACKNOWLEDGMENTS.....	3
FIGURES AND TABLES	9
CHAPTER 1 INTRODUCTION.....	10
What is Tuberculosis?.....	12
The History of TB in New Zealand.....	13
Who gets TB in New Zealand.....	14
TB Reactivation	15
Treatment of TB.....	16
Anthropology and TB	16
CHAPTER TWO THEORETICAL CONSIDERATIONS.....	19
Who are Pakeha?.....	19
Being Pakeha, Studying Pakeha.....	20
The Culture of Biomedicine.....	21
Attitudes to Health and Illness - We Are Not Empty Vessels.....	22
Explanatory Models	23
Classifying the Sick.....	24
Stigma.	25
<i>Agency and Resistance in the Face of Stigma.....</i>	<i>26</i>
Life History	28
Conclusion	29
CHAPTER THREE RESEARCH PROCESS.....	30
What I Bring to the Study	30
The Developing Question	30
CHAPTER FOUR BEING HEALTHY, BECOMING ILL.....	37
Being Healthy.....	38

<i>Paired Interviews</i>	38
The Meaning of Health	38
The Meaning of Illness.....	39
Health Responsibility	40
Causes of illness	41
Becoming Ill.....	44
<i>How Did You Know You Were Ill?</i>	44
<i>Frank's Story</i>	45
<i>When It All Goes Wrong</i>	48
What Caused your Problem?.....	49
<i>Reflecting Back on 'First Time' TB</i>	49
Explanatory Models	53
The Process of Diagnosis	55
Self-Diagnosis, Jumping to Conclusions ... "It May be Cancer"	55
A Diagnosis at Last	56
<i>"My Friends Knew I had Something"</i>	57
<i>Being Told that you have Tuberculosis</i>	58
CHAPTER FIVE GETTING TREATMENT.....	60
Going to Hospital	60
Hospital Life.....	61
Adjustment to the Medication	64
Patient Education	65
Community Care of Tuberculosis	66
Side Affects of Medication	70
<i>You Don't Feel Like Doing Much</i>	70
<i>Gout</i>	70
<i>Alcohol and Medication</i>	71
<i>Mental Clarity</i>	72
The Sick Role.....	72
Taking Tablets, Managing Time	73
Finally Ending Treatment	73
Having a Drink Again.....	74

<i>Mavis' Miracle Drug Makes a Marvellous Christmas</i>	74
<i>I Had To Give Up Drinking</i>	75
Life After TB.....	75
<i>A Different Person</i>	75
<i>Biographical Disruption</i>	77
CHAPTER SIX MANAGING STIGMA.....	81
Tuberculosis has been a Stigmatised Disease in New Zealand.....	81
New Zealand History of TB and Stigma.....	82
Whether my Participants had Experienced Stigma	82
Isolation Caused by Stigma.....	83
Effect on Family.....	86
‘Managing’ Stigma.....	87
Exposure to TB - Citizenship and Public Health	88
Experience Counts when it comes to Managing Stigma and Healthcare.....	90
Self-Assertion in the Face of Medical Dominance	91
It's <i>They</i> That Have the Problem.....	92
Community Attitudes to Tuberculosis	93
Disclosure.....	95
Sources of Health Information.....	96
CHAPTER SEVEN DISCUSSION AND CONCLUSION	102
Time and Tuberculosis.....	103
Tuberculosis and the Elderly.....	107
Cure sans Healing	107
<i>Biomedicine and Cure</i>	109
<i>Talking Past Each Other</i>	111
<i>Healing as the Restoration of Reserves</i>	111
Treatment Vigilance.....	112
Care	113
<i>DOT, a Standardised Model</i>	115
<i>Networks of Care</i>	116
Conclusion	117

REFERENCES 118

FIGURES AND TABLES

Table 1 Tuberculosis Notifications and Age Specific Rates by Ethnicity, 2002.....	17
Figure 1 Medicine Information Chart.....	71
Figure 2 TB in the Media.....	91

CHAPTER 1

INTRODUCTION

“You think it’s a dead and gone thing in New Zealand”

I climbed the steps to the front door of her sunny home autumn last year bearing my offering of hot cross buns. I was greeted at the door by a woman resembling my own grandmother who began her story before I reached my chair. As she made me a cuppa she called across the kitchen telling me that her mother was a nurse in a small rural community in the South Island. Their home was in a rural valley, it was very damp and foggy, so much so that in winter icicles three feet long decked the veranda and would last all day if the sun did not get to them. When her mother was taken to hospital by ambulance with tuberculosis it was so damp that she and her father could squeeze water out of the mattress. Mother was admitted to hospital with TB in both lungs. She was there for some months and was offered an operation to collapse the lung. This was a new procedure at the time but the previous four cases had died and mother declined the operation because she wanted to be with her children. Mary was aged thirteen and her younger brother, seven years old. She only wanted to come home. They all moved to Auckland to a better climate for mother and Mary left school to nurse her for two years until she died. Dad worked and Mary minded her during the day. After she died Mary fretted awfully. Father and children were x-rayed and it was found that Mary had a shadow on the lung ... I raised the courage to stop her amid the mesmerizing narrative and asked permission to tape the unfolding story. We sipped tea as another life of TB emerged.

Despite the discovery of effective treatment fifty years ago, tuberculosis (TB) infection continues to affect one third of the world’s population, resulting in three million deaths per year (Gandy and Zumla 2002:385). Recent changes in the global distribution of tuberculosis have stimulated increased interest among people in the industrialised world toward the control of the disease. The resurgence of tuberculosis in industrialised cities in the 1980s and 1990s after periods of decline has focussed attention on the magnitude of the

problem so that in 1993 the World Health Organisation declared TB a global emergency (Ravigalione 2003). New Zealand has also experienced an increase in TB since a low in 1988. The national rate of TB disease was 10 per 100,000 in 2003, with an average annual notification rate of 23 per 100,000 for Auckland where this research is located (Sneyd and Baker 2003). As part of a larger project, this research concerns those of Pakeha ethnicity who comprise the largest population group in New Zealand yet have the lowest rate of tuberculosis. Friends and acquaintances have been surprised to hear about my study, perhaps because the past historical decline in tuberculosis in New Zealand has contributed to a belief that it is a 'disease of the past' or, that it relates only to immigrants: 'others' from outside New Zealand. These attitudes in the community are particularly strong for Pakeha.

Last year 39 Pakeha people suffered the disease and most are new cases acquired in New Zealand. Pakeha cases of TB make up 10 per cent of all cases of TB disease (Sneyd and Baker 2003:75). The invisibility of Pakeha TB obviously has consequences for these sufferers in coping with the disease and in accessing treatment. In conversation with an elderly person in my social network I learned of the "secrecy surrounding TB in [her] younger days" (about 60 years ago) and that her parents refused permission for her to wear a Holy Communion veil given to her by neighbours who, she now knows, had suffered TB. I was shocked to know that people have been ostracised here in New Zealand where medical treatment has been available for TB since World War Two. This stimulated a particular interest in stigma concerning TB sufferers today in the Pakeha group under study.

I set out to achieve this end by conducting focussed interviews with nine participants who have recently had tuberculosis. As the underlying health culture of a group informs their ways of dealing with illness, I also interviewed paired participants who were matched according to age and gender and occupation with the TB participants about their conceptions of health, illness and tuberculosis. The aim of this thesis is to investigate the experiences of Pakeha with TB disease in Auckland.

Tuberculosis is a disease that has the ability to continue to effect people for long periods of time, and also requires long periods of drug treatment. I will argue that the experience for the TB sufferer takes place in a wider community that continues to stigmatise TB, albeit on a different basis than in the earlier lives of the elderly with whom I talked. The low incidence of TB for Pakeha and community attitudes that stigmatise migrants and blame health problems on outsiders has caused Pakeha TB to be invisible and

this has implications for a timely diagnosis and adjustment to a disease people perceive as relating to the 'other'. For Pakeha, TB is principally a disease of the elderly and a timely diagnosis is vital if treatment is to succeed. The conceptions of health and illness held by this dominant group are strongly influenced by biomedical theory and generally carry an underlying belief in health as a reserve that intersects with biomedical notions of the immune system. This was evident in explanatory models of TB participants and was again raised by participants in connection with the aftermath of their cure. As a group who were successfully cured of TB, all participants cited the significant level of support and care from Public Health Nurses (PHNs) as a factor in their compliance with treatment. Nevertheless the experience of TB caused significant biographical disruption for some in coming to terms with a changed post-illness identity.

What is Tuberculosis?

The biomedical explanation rests on the discovery of the tubercule bacillus by Robert Koch in 1882. The bacteria enter the body through the lungs after inhalation of the bacillus in aerosol form from a person with active TB disease. TB is spread by droplet infection when a sufferer is singing, talking, sneezing or coughing in a confined space, usually over an extended time period (Klov Dahl *et al.* 2001). Therefore there is a higher rate of transmission among people living in close proximity. The initial infection may progress to disease as pulmonary tuberculosis or less commonly to any other sites around the body as extra-pulmonary TB. Tuberculosis infection is said to affect one third of the world's population today and in most cases they are unaware of it. Many of those infected will complete their lives without developing TB disease however social stressors such as poverty and malnutrition and compromised immune systems support the transition to TB disease. Those with TB disease commonly experience respiratory problems including night sweats, symptoms that can be attributed to other illnesses. However, left untreated TB disease can be fatal and is the second highest cause of death from infection in the world (Roberts and Buikstra 2003:11). In New Zealand, there was a decline in the hospitalisation and deaths of those with TB during the period 1995-2001. However, as the ethnic group with the highest longevity and TB incidence in over 70 year olds, Pakeha also have the highest death rate due to TB in this age group (Turnbull 2003). There were six deaths of 348 cases of TB disease in 2002.

The History of TB in New Zealand

At the time of the colonisation of New Zealand tuberculosis was rampant in European cities. Many settlers brought the disease to Aotearoa/New Zealand as they escaped poor working and living conditions that were prevalent during the industrialisation of cities. Inevitably TB spread in New Zealand and Maori people were disproportionately afflicted by the end of the 19th century when the Department of Public Health was conceived. However attention to the health of the public did not include rural Maori. Their rates of tuberculosis were found to be at least ten fold that of Pakeha once documentation of their health status began in the 1930s (Bryder 1994:327). Similarly, marginalised groups such as Maori began to be a concern lest they spread disease (Bryder 1994:324). Medical and political debate arose at the turn of the century when New Zealand was being promoted as a healthy country for consumptives to emigrate to from Britain, at a time when fresh air and a warm climate were the mainstay of ‘taking the cure’. Indeed, the problem of immigrants ‘bringing disease in’ is a familiar cry today. When sanatoria were opened in the early 20th century they catered for those Europeans of good moral fibre in the early stages of tuberculosis; the most advanced cases remained in the community. Treatment in sanatoria relied on “good food, fresh air, rest and ‘graduated labour’” (Bryder 1991:81). Similar values were stressed as part of a campaign against tuberculosis that centred on household cleanliness, the prohibition of spitting, community education and notification of TB. A further series of public health measures followed.

Health camps were first set up in 1922 for malnourished children amid concern with the fitness of the next generation and were expanded and funded through the sale of Christmas seals. A significant move toward reducing tuberculosis was the provision of state houses that began to be built after initiation by the welfare state in 1936. Preference was given to families with tuberculosis. Provision of state housing for Maori followed. Pasteurisation of milk began and by 1944, 70 per cent of milk sold in Auckland was pasteurised as a measure against bovine tuberculosis. By the time streptomycin became available in 1947 tuberculosis was already on the decline for all groups although wide disparities still existed between Maori and Pakeha case rates. The BCG vaccination against tuberculosis for school children began in the 1950 and although discontinued in schools in 1980 it is still recommended soon after birth for babies considered at high risk of TB. The decline in TB caused the sanatoria to close in 1957. The numbers of TB cases continued to fall until in 1972 when it was again recorded that immigrants were causing a

rise in notifications, notably Samoan overstayers, although medical opinion varied as to whether TB was in fact contracted in New Zealand (Bryder 1991:87).

During the 20th century the decline in tuberculosis was attributed to improved socio-economic conditions. However the incidence for Maori and Polynesian people in 1983 was nine and four times that of the majority population respectively. Pakeha benefited more than Maori from public health measures in the early 20th century that “aimed to improve the quality of the white population” (Bryder 1994:328). The reduction in Maori tuberculosis has been accorded to improved living standards alone (Wells 1991). Nevertheless there has been a recent increase in New Zealand born cases of TB in 1995. New Zealand has experienced the fastest growth in income inequality compared to other OECD countries. The gradient in health has been linked to income disparity as well as the actual level of income (Howden-Chapman and O’Dea 2001:133, Turnbull 2003:10).

A recent contribution is a study of the relationship between social capital and tuberculosis that has found that those with least social capital are more vulnerable to disease. Social capital is generally defined as “trust, reciprocity, and cooperation among members of a social network that aims to achieve common goals” in recognition that, “social networks have value” (Holtgrave and Crosby 2004:Page no?). However, this is a controversial topic as Pearce (2002) has shown. The argument that high income inequality reduces social capital and negatively affects life expectancy is under debate. Pearce (2002:1) has stated that “the income inequality/social capital theory was always questionable and although they play a minor role, the new evidence indicates that they are not the major determinants of population health” initially thought.

Who gets TB in New Zealand

In 2002 the rate of tuberculosis was 10.3 cases per 100,000 cases, with a similar rate of 10 per 100,000 the previous year. The highest rate (74.4 per 100,000) was in the group designated as ‘other’, the next highest were Pacific peoples (34.9 per 100,000) with lower Maori (12.3 per 100,000) and Pakeha (1.5 per 100,000) rates (Sneyd and Baker 2003). New Zealand statistics show the incidence of tuberculosis in New Zealand for Pakeha by age in 2002 is highest in the over 70 year age group (see Table 1) and similarly for Maori the 60-70 year age group are most affected (Sneyd and Baker 2003). It is not uncommon for TB in the elderly to be diagnosed post-mortem (Zevallos and Justman 2003:129). In fact New Zealand research concerning diagnostic delay has shown that of 134 cases of adults with pulmonary TB in 1996-1998 period, six were first diagnosed post-mortem

(Calder *et al.* 2000a:484). High and rising rates of tuberculosis in the elderly are occurring in many developed countries e.g. Scotland, Switzerland and this has been explained by an aging population who were infected with TB in their youth when TB was endemic (Duffield *et al.* 1996:140). As the number of elderly in New Zealand continues to rise there is a likelihood that tuberculosis in nursing homes will increase, as has occurred in America.

TB Reactivation

In 2002, four out of five cases of reactivation TB in Pakeha occurred in people aged 70 years and over who had TB disease in earlier years when available treatment was different (Sneyd and Baker 2003). It is important at this stage to clarify the terminology with regard to these two categories of TB that are seen in aged people. Recorded reactivation TB disease in New Zealand refers to a reactivation of TB *disease* (that has most often been treated before). However the term is sometimes also used to describe the conversion of latent TB infection to active TB disease, often many years later. Most cases of TB infection remain unknown unless they convert to disease and are then notified as new disease. In USA in the early 20th century, approximately 80 per cent of the population were infected with tuberculosis by the age of 30 years because of the level of TB disease in the community (Yoshikawa 1992:178) and a similar situation existed in New Zealand. As people with TB infection age, TB disease can develop due to immune stress. A person's immune status may be reduced due to age or malnutrition, cortisone treatment and other diseases, alcoholism or poor living conditions. If the diagnosis is delayed the risk of infection to others in close contact is a concern and for the sufferer the effects of the disease are exacerbated.

Tuberculosis disease is more difficult to diagnose and treat in elderly people (Packham 2001:176). Classic symptoms may differ and be masked by pre-existing illness, indeed two of the elderly participants in this study were discovered to have tuberculosis while hospitalised for other problems, notably a bleeding stomach ulcer, malnutrition and alcoholism and in another case, pneumonia and heart problems necessitating bypass surgery.

In this study four participants aged over 70 years had suffered TB in their youth, at which time they received the treatment of the day. This is a higher proportion than expected. Between 1995 and 2002 14 per cent of TB cases among Pakeha elderly (65 years and over) were reactivations. Reactivation of TB disease is unusual with

contemporary drug regimens. Former treatment for these participants in the post-war period ranged from a two year stay in a sanatorium to six months of daily streptomycin injections accompanied by PAS medication in 1960. There is scant reference in TB literature to the reactivation of TB in people who received former drug regimens. There is however growing concern in overseas biomedical literature about aging and increased TB that emphasises the conversion of TB infection to disease, its under estimation, and the difficulties posed for diagnosis and treatment (Duffield *et al.* 1996, Harper 1999, Janssens and Zellweger 1999, Packham 2001, Rajagopalan and Yoshikawa 2000, Scullion 2000, Stead 1998, Zevallos and Justman 2003).

Treatment of TB

Treatment for TB disease is a long-term process (up to 12 months for some participants) involving multiple drugs. Patients with active infection are admitted to hospital until the treatment overcomes their contagious status. At this stage their ability and willingness to manage self-medication at home is assessed, to determine whether or not they will be placed on DOT. The strategy of Directly Observed Therapy (DOT) was implemented by the WHO in response to declaring TB a global emergency. It encompasses “political commitment to sustained control of TB, access to sputum microscopy, short course chemotherapy using direct observation of treatment, an uninterrupted supply of drugs and a recording and reporting system (Garner and Volmink 2003:pg no.?). In New Zealand treatment for tuberculosis is free but sufferers must bear the costs of being away from employment, transport and time required to attend outpatient appointments. The DOT strategy is recommended for TB sufferers who are unable or unwilling to self-medicate, have TB reactivation or drug resistant TB, or have TB that is resistant to *rifampycin*. Consideration for DOT may also be made when the disease is extensive, people lack social support or have a complicated treatment regimen (Calder *et al.* 2001). DOT is administered by Public Health Nurses (PHNs) who visit their clients at home twice weekly after discharge from hospital and also visit clients on self administered treatment. Over the long course of treatment a supportive, interpersonal relationship is usually formed.

Anthropology and TB

To be effective, a strenuous treatment program such as DOT must accord with the context in which people live. Adherence or compliance with completion of the long treatment has become a major issue in biomedical discourse about TB and saw the development of DOT. In some literature the term adherence has replaced compliance however I have retained the

original because the intended meaning is not altered and the term compliance is freely used locally by PHNs. However a qualitative approach to tuberculosis research is able to add a vital dimension to knowledge of the sufferer's experience of the disease that is absent in biomedical literature. As Fitzgerald and Park (Fitzgerald and Park 2003:2) have noted, anthropology is able to contribute a critical approach that covers socio-economic, cultural and political aspects of health issues that can illuminate the context TB treatment in the everyday lives of the sufferers and their families.

Since control of TB continues to be an important growing health issue in New Zealand, research into the meanings and understandings it holds for sufferers who are embedded in their own cultures of health offers an important perspective on treatment compliance issues. In a recent critique of the tendency to study the culture of minority ethnic groups in deficit terms, Blakely (2004) makes recommendations that are relevant to this research about Pakeha with TB. " Research and understanding of the beneficial effects of Pacific culture (and both Maori and the dominant Pakeha culture) on health is required in New Zealand, not just for its own intrinsic value but because it may identify positive policy options for reducing inequalities in health (Blakely and Dew 2004:1). This research aims to illuminate of the way Pakeha cultures of health affect their management of TB disease as it has to date been largely ignored.

Table 1. Tuberculosis Notifications and Age Specific Rates by Ethnicity, 2002

Ethnicity	< 20 Years age group per 100,000	20-69 age group per 100,000	70+ age group per 100,000	Total TB Cases per 100,000
European	0.1	1.4	4.9	39
Maori	4.4	29.1	31	65
Pacific Peoples	31.5	39.1	4	70
Other	16.4	93.3	10	184
Unknown				26
TOTAL	52.4	162.9	49.9	384

Based on Sneyd and Baker (2003:75)

CHAPTER TWO

THEORETICAL CONSIDERATIONS

“Somehow the tuberculosis came through my immune system”

It is notable that literature concerning the illness experience of tuberculosis seldom addresses the position of members of the mainstream cultures of developed countries. This chapter discusses Pakeha as the majority group in New Zealand and the theoretical approaches I will use to explain my findings. Theories relate to conceptions of health and illness, stigma, power and difference and critical interpretive anthropology.

Who are Pakeha?

Pakeha is the contested term used to describe New Zealanders of a European heritage whose “cultural values and behaviour have been primarily formed from the experience of being a member of the dominant group of New Zealand” (Spoonley, 1988:63 cited in Bell 1996:147) Some Pakeha are not comfortable with a Maori term because they resist being ascribed their identity by another cultural group. In general usage the term does not include immigrants or individuals who continue to maintain strong linkages, ways of speaking and customs of their former homeland, often through cultural clubs and the celebration of significant shared rituals (Fleras and Spoonley 1999:83). The value of the term Pakeha is that it denotes a relationship that is not defined by its own dominant position.

As the largest category with political and economic dominance, Pakeha have often not been accorded ethnicity, in part because the group has not believed they possessed a culture of their own, seeing it as a facet of the ‘other’, of minority ethnic groups (Fleras and Spoonley 1999:84). According to Balibar (1991:25), to overlook the ideologies of the dominant group and assume their universality is to perpetuate their hegemony. Similarly, Laura Nader (1988) has challenged anthropologists to take on opportunities to “study up” or “sideways” in their own society to give a broader context of the origins of problems that are not always made clear by studying a minority group in a non-comparative way. I am

adopting MacDonald's (1999:113) definition of culture as "the way in which human groups create and share explanatory systems about the world in which they live and the ways in which they act according to their shared understandings".

Anderson (1996:262) writes about the "fuzzy" categories that race and ethnicity provide. Ethnic group is not a biological category it refers to social and cultural affiliation that may alter in place and time. However, I have used the term Pakeha in regard to participants who may not have specifically identified as such. I use the term in reference to any New Zealander of European extraction. While the TB participants all ascribed their ethnicity on admission to hospital, the paired participants were chosen through my own social networks and were not specifically asked about their ethnicity. The fuzziness of the categories used are inherent when considering that one paired participant came to New Zealand from UK as a young adult, evident because she still speaks with a slight British accent.

Being Pakeha, Studying Pakeha

In approaching the study of Pakeha, as a middle-class Pakeha myself, I am studying my own culture which means that I am well placed to meet the criteria for interaction that include "1) physical proximity of the fieldworker to the people he studies, 2) knowledge of their language and 3) psychological involvement" (Powdermaker 1966 cited in Nader 1988:480). This does, however, present other challenges such as really listening for particularities that one may easily take for granted. Studying one's own culture has been termed "auto-anthropology" (Strathern 1987:18) in which the indigenous researcher endeavours to set aside their own cultural preconceptions by adopting anthropological approaches that allow for critical self-reflection. I learned a lot about tuberculosis and associated conditions from the participants, many of whom seemed keen to 'enculturate' me into the world of TB of which I had no experience. As a novice researcher, at times my inexperience was revealed. For example, I got the 'run around' on one occasion when I obliged a TB participant (who also suffered from alcoholism) by literally running to the shop to get milk for her during which time she fixed another drink.

New Zealand's colonial history has placed the wellbeing of Pakeha in a position of advantage and this is often only acknowledged when confronted occasionally by a Maori academic, such as Paparangi Reid who recently called for a reduction in Maori health disparities. This caused a defensive reaction by some Members of Parliament who took

exception to her assertion on radio that Pakeha have “banked all the improvements” in health (Reid 2003).

The worldview of the dominant group was taken-for -granted as the universal norm until a political shift occurred in the 1980s when “Pakeha moved from seeing themselves as colonised (in relation to the British) to a perception of themselves as colonisers in relation to Maori”(Fleras and Spoonley 1999:86). A critical reflection on Pakeha cultural practices has raised the awareness of their potential to dominate in government institutions (for example, the Royal Commission on Social Policy 1998) and it has led to an evaluation of policy effects on Pakeha-Maori relations that has had ongoing effects on practices of ‘cultural safety’ by health providers for all ethnic groups (Fleras and Spoonley 1999:88). However, cultural safety within the health sector cannot alter socio-economic disparities between Maori and other New Zealanders.

The economic dominance of Pakeha is demonstrated by a household income differential by ethnicity for Pakeha that is 5-6% higher than the overall average, the income for Maori and Pacific people being 80% of the NZ average as shown in the 1996 census (Howden-Chapman and O’Dea and O’Dea 2001:141). In using these averages one must however remember that there are also Pakeha who are socio-economically depressed and that in general “ tuberculosis affects the poorest and the most vulnerable sectors of communities the most”, irrespective of ethnicity (Turnbull 2003:10). In Auckland this has been reflected geographically by a correlation between the least affluent parts of Auckland and higher rates of tuberculosis (Public Health Protection Auckland Healthcare 2000).A recent review of the anthropology of health inequality put it succinctly: “affliction must be understood as the embodiment of social hierarchy” (Nguyen and Peschard 2003:447).

The Culture of Biomedicine

In reflecting dominant western values, biomedicine is focussed on the disease process in the individual body, often to the exclusion of environmental causes of disease such as pollution or the relationship of disease to socio-economic inequities. Because biomedicine frequently pursues the causes of ill health at a micro level of microbes, hormone imbalances and the resulting treatments often relate to pharmacological cures. The social settings that produce susceptibility usually are not highlighted, deferring a need for structural changes (Dew and Kirkman 2002:22). An ethnographic approach has the potential to understand the sufferer’s experience in the context of their everyday living environment and is now being hailed as a necessary adjunct to the biomedical approach in

conjunction with pharmacological cures for tuberculosis (Lienhardt *et al.* 2003:203, Sumartojo 1993:1313).

Attitudes to Health and Illness - We Are Not Empty Vessels

When people decide to access medical opinion for an illness they do not approach doctors for advice as “empty vessels” (Lupton 1994:100) to be filled up with the ‘correct’ knowledge. They arrive as a result of their personal hierarchy of resort that is grounded in pre-existing conceptions of health and illness, often under the guidance of ‘trusted others’ i.e. their social network. It is accepted that there is a difference in the healing knowledge between professional and lay people; however an ethnographic approach focussed on lay people with health problems serves to shift the attention from the healthcare provider perspective to the sufferer who is, after all, an expert in their illness experience. Kleinman (1980:73) promotes the separation of lay and professional models, namely illness and disease. Illness represents the subjective, lived experience of the sufferer while disease is biomedically oriented and depicts a technical malfunction of body processes (Calnan 1987:9, Helman 1990:91, Kleinman 1980:73)

Everyday ways of thinking about health and illness are dynamic, construed from personal experience, the attitudes of members or family and social networks, formal education, history, popular discourse and so on; they are culturally informed. It is important to be aware of these normative perceptions of health for Pakeha as they contextualise conceptions of tuberculosis for those that suffer from TB disease. Attitudes to health potentially inform decisions to seek help toward timely diagnosis, affect interaction with health providers and adherence to treatment regimens as well as satisfaction with the medical management of sickness episodes. The media coverage of biomedical approaches to disease and the availability of medical knowledge in popular reading, education, advertising, and via computer technology has ‘closed the gap’ somewhat so that in developed countries health attitudes of the general public have been shaped toward a disease orientation as biomedical knowledge is grafted onto existing beliefs of health and illness (Blaxter 2000b:26). However, it should be remembered that notions of Western or ‘developed’ biomedicine are not always consistent due to the cultural variations in their places of origin (Helman 1990: 65, 89). Anthropological approaches to health and illness view culture as a lens through which attitudes are mediated in the context of social, historical, economic, political and environmental factors (Helman 1990:7).

Explanatory Models

Attitudes to certain disease processes are culturally informed and inherent variables exist between different actors in the health-seeking process. (Kleinman 1980:106) developed the concept of “explanatory models” as a frame to elaborate the differing meaning of a specific illness for sufferers, their families and practitioners. The explanatory model of TB for the biomedical professional will differ from the explanatory model of the sufferer and the interactive healing process must bridge the difference between these two ways of thinking. The consultation process will also be influenced by variables of time and place, class and gender of those involved (Helman 1990: 95). The explanatory model consists of perceptions about the cause and timing of a particular sickness, how it affects the body, its expected course, severity and treatment. intended “the explanatory model technique to be a device that would privilege meanings, especially the voices of patients and their families, and that would design respect for difference” (Kleinman 1995b). As biomedicine itself has a “cultural orientation” then practitioners too have explanatory models that often do not express “what is at stake in suffering”(Kleinman 1995b).

The purpose of eliciting explanatory models is not to replace them with a more biomedically “correct” one. The process of understanding the meaning that an illness holds for the sufferer can ensure a heightened understanding and respect for the patient in the healing context and illuminate conflicting perspectives between the models of the patient and practitioner that may require sensitive discussion toward successful treatment outcomes (Kleinman 1988:49). This is not to be confused with the Health Belief Model that (Good 1994:7) critiques because of the underlying assumption that the erroneous ‘beliefs’ will be ‘fixed’ with biomedical knowledge in the hope that compliance will logically follow. To adequately use explanatory models in improving TB outcomes (Rubel and Garro 1992:635) point out that they are of little use on their own and the cultural meanings of TB should be related to other variables concerning treatment seeking decisions such as structural factors. Explanatory models become merely descriptive if they are not situated in the context of the power relations that inform them.

The explanatory model of an illness must also be seen in the socio-economic context in which the sufferer conceives it. For example, Helman (1995) shows that the perceived severity of an illness will be influenced by how it will potentially affect everyday life. The perceived origin of the illness, the work situation of the sufferer, whether they can take paid leave, have health insurance and the degree to which the state provides health care and sickness support. Shared cultural models of illness inform and are

informed by individual specific explanatory models and both are founded on underlying perceptions about health and illness that may change over time (Garro 1988:98)

An alternative way of thinking about health and illness perceptions has been presented by Cornwell (1984) who conducted research among working class families in London and found that in order to deal with the pressures of moral judgement about the legitimacy of illness explanations, participants had two constructs, a private account and a polite publicly acceptable version depending the context and on their rapport with the researcher. This was in part due to participants' perception of academics involved in research as 'experts' in health that required a level of "information control" by participants to protect their legitimacy (Cornwell 1984:15-7). These effects of perceived unequal power relationships are not addressed in explanatory models.

Classifying the Sick

The power relations that exist between patient and professional are inherent in a setting of biomedical dominance (Pappas 1990). In my experience (as a middle-class Pakeha woman) the power differential experienced in a medical consultation always favours the professional and can lead to a lack of time or trust, preventing the ill person from asking questions to ensure understanding or from asking further questions. Indeed, people often complain that they forget their questions in a consultative situation where they feel a lack of autonomy. My research, therefore, includes some observations of clinical encounters, as well as discussions with participants about their experiences of them.

The power differential in patient-doctor interactions is normalised in Parson's (Parsons and Renee 1958:236) structural functional analysis of the sick role as a form of deviance. Acute disease is a 'social event' and the sick role legitimatises a withdrawal from duties and requires the assistance of others to overcome the illness. In return, the sick person must want to recover and seek legitimate technical help (Davis and Dew 2002:26). The role of the sick person is passive and the doctor's power is legitimated by the possession of superior knowledge and the regulatory responsibility for curing the sick person so that they may again fulfil their former role in society.

It is not only the docile sick who are subjected by the medical gaze in Foucault's analysis of medical control (Foucault 1977:144). The subjectification of the docile body as a measure of social control has been the outcome of changes in regimens of discipline through history that have moved from physical methods of punishment and compulsion toward methods that induce self-regulation. The individual controls the self so that "he

simultaneously plays both roles; he becomes the principle of his own subjection” (Foucault 1977:203). This self-regulation is a facet of bio-power (seen in the ‘new’ public health) that replaced the terrible power of the sovereign over life, with one that embraces a technology of self-administration (Foucault 1977). Healthy individuals’ everyday activities are controlled through bio-power working within to manage lifestyle choices to control risk factors and avoid the sick role (Lupton 1994:107). However even the ‘foolproof’ control of medication administration devised as DOT fosters resistance in the form of non-compliance, an inevitable effect of power.

Knowledge of populations is generated about individual bodies through their testing, measurement and classification as a means of “regulatory control” (Foucault 1998:139). Surveillance of bodies is the work of public health institutions that carry out TB surveillance today. According to Foucault (1977:198-9), the labelling of the normal follows the establishment of categories of difference. This labelling serves to exclude those who exhibit “dangerous mixtures” through a form of “binary branding” or labelling that is found in association with stigma.

Stigma

The term stigma is derived from the Greek practice of drawing attention to the defective morality of a slave, criminal or traitor by imposing an external mark or brand to signify to others their blemished state. Historically, tuberculosis has been a stigmatised disease in New Zealand among Pakeha. The classic work: *Stigma: Notes on Management of Spoiled Identity* by sociologist, Erving Goffman (1963) is the a foundation from which much subsequent writing has developed. As the title suggests, the effect of stigma on a person’s identity prevents the enjoyment of full social acceptance, the stigmatised are devalued from without and within, rendering them “reduced in our minds from a whole and usual person to a tainted and discounted one” (Goffman 1963:12). Goffman (1963:13) therefore refers to stigma as “an attribute that is deeply discrediting” although he also notes that “a language of relationships, not attributes is really needed”. Stigmatised people whose attribute is hidden may develop strategies of “information control” in order to postpone “disclosure” and “pass” as normal (Goffman 1963:14). People who exhibit expected behaviour are classed as “normals” by Goffman (who includes himself in this group). Normals discriminate against the stigmatised person, “reducing his life chances” in the belief that the stigmatised is “less than human” (Goffman 1963:15). To manage the perceived danger the outsider presents, normals are prone to attach other attributes such as

social class or ethnicity to the discrediting attribute as part of the construction of an ideology to justify the inferiority of the person. A master status, a label such as 'consumptive' has the potential to 'spoil' a person's perceived identity, all other aspects being disregarded in favour of the stereotype (Coleman 1986:219, Goffman 1963:15, Link and Phelan 2001:6, Lock *et al.* 2001:4). It follows that strategies to minimise the stigma associated with TB have been enacted, such as renaming outpatient clinics attended by TB sufferers to Chest Clinic at Greenlane Hospital.

Agency and Resistance in the Face of Stigma

Recent stigma literature has emphasized the essential component of power in relation to the stigmatizing process. An anthropological study of stigma and leprosy sufferers by Gussow and Tracy (1968) demonstrates the active resistance by victims of stigma. The adaptive response of the highly stigmatized leprosy sufferers to "dissonant and discrediting views from without" was to create their own ideology of stigma to "disavow their imputed inferiority and danger" (Gussow and Tracy 1968:pg no?). Joan Ablon (1981) in her article *Stigmatised Health Conditions*, highlights the contributions that anthropologists can make in revealing the variation of human experience of stigma across cultures not always acknowledged in descriptions. However there has been very little other research completed about the effects of the stigma of TB on dominant Western cultural groups.

Reissman (2000:3) critiques the Eurocentrism and lack of accommodation of individual agency and power in Goffman's theory in her analysis of the experience of childless women in South India. She points out that these women cannot choose "group alignment" (Goffman 1963:137) that allows solidarity with other women or privacy that allows for "timed disclosure", taken-for-granted in many individualised cultures in the West. Her fieldwork revealed the ways that "economically impoverished South Indian women who are involuntarily childless resist, stop, and survive victimisation" (Reissman 2000:11). In a pronatalist society they faced extreme antagonism that compelled women to sometimes leave living arrangements with hostile in-laws (taking their husbands) and return to their natal villages despite norms that required deference to mothers-in-law. Their reaction to the stigma of infertility was one of resistance.

There has been a focus on the psychology of stigma, particularly in relation to the mentally ill. A recent study by (Camp *et al.* 2002:830) about the lived experiences of women with chronic mental illness found that many women rejected dominant stigmatising attitudes. Because they did not internalise or adopt the attitudes of the

majority toward their illness, they refused to take on a master identity (e.g. as depressives) or “see themselves as others do” as proposed in Goffman’s interactionist approach (Camp *et al.* 2002:2). The move by some writers to return to the concept of stigma as constituting a *relationship* that is devalued rather than as a mark, attribute, or a thing, is evident in some recent literature (Parker and Aggleton 2003:14, Link, 2001 #253:363) I suggest that in part, confusion has been due to the dual references in Goffman’s text to stigma as “an attribute that is deeply discrediting” when he also states that “ a language of relationships is what is really needed” (Goffman 1970:13).

Situating stigma within a broader context to show relationships of power and domination it facilitates a picture of the ways in which dominant groups to maintain control. The political, economic, cultural and social forces that underlie stigma are implicit in the following definition offered by Scheper Hughes:

Stigma is discourse, a language of human relationships that relates self to other, normal to abnormal, healthy to sick, strong to weak. It involves those exclusionary, dichotomous contradictions that allow us to draw safe boundaries around the acceptable, the permissible, the desirable, so as to contain our own fears and phobias about sickness, death and decay, madness and violence, sexuality and chaos. The tactics of separation allow us to say that this person is *gente*, one of us, and that person is *other*. (Scheper-Hughes 1992:374)

In fact if Foucault and Goffman are read together, an understanding of stigma can be gained as it acts at “the intersection between culture, power and difference” (Parker, Aggleton 2003:17). Stigma often plays a role in the producing difference. Difference is promoted through the institution of bio-power in the process of producing normal and abnormal categories as part of systems of classification provided for by the human sciences. Those that are different are separated out, they are excluded (Foucault 1977:199,223). A focus on discrimination from outside shifts the responsibility from the stigmatised person to adapt and allows for resistance strategies to be expounded that were outside Goffman’s model. A change of focus from behavioural and psychological analysis of stigma toward social processes can offer new intervention possibilities for stigma and discrimination reduction (Parker and Aggleton 2003:20).

Health is a primary means of conceiving identity for the contemporary middle class and to do this we set up internalised ‘boundaries’ that foster the ‘control of the self’ exemplified above, through techniques of bio-power. This results in a “closing off” of community and in the process the “other” is subordinated due to a perceived “threat of

incursion” by those who correlate self-control of body with health (Crawford 1994:1364). By stigmatising the “unhealthy other” the majority group (Pakeha), use health as a way of defining how they identify themselves. The threat of TB from immigrants has been a common perception in talking with Pakeha about TB, even by those who have acquired the disease in New Zealand. The fear of the “diseased other” is inflated by frequent referral to immigrants as a health threat in Parliament by MP Winston Peters (Peters 2003).

Life History

National statistics show that tuberculosis disproportionately affects some groups more than others; ethnicity intersects with age and socio-economic status in different ways for each group. The Pakeha category show a concentration of TB disease at later life stage due to the nature of tuberculosis bacillus. Infection can remain latent for many years; this is pertinent to consider stressors at earlier life stages when initial infection may possibly have occurred. Life history theory postulates that each life stage is affected by the one before. In a life history approach to inequalities in health (Wadsworth 1997:857) notes that it is possible that “the roots of health inequalities lie in biological and social experience at the earliest times of life”. The personal and social histories of the World War Two era and the level of tuberculosis in their childhood communities have particular relevance to the present health of elderly TB sufferers. It is therefore important to that interviews encompass a participant’s life history to include health influences of earlier life-stages. Childhood exposure to poor nutrition or housing, due to socio-economic factors or WWII food rationing may have influenced vulnerability to tuberculosis infection. Similarly, respiratory health affected by parental smoking behaviour, occupation and atmospheric pollution can have cumulative effects at a later life stage (Wadsworth 1997:862). A theory that deals with factors of time may explain the present situation of tuberculosis disease.

Critical Medical Anthropology

A meaning centred micro-level approach of the experience of illness is incomplete if it does not also consider the wider political economic, cultural and historical context that contextualises the realm of the tuberculosis sufferer. The everyday life experiences that make up the ‘local moral world’ of the sufferer can be interpreted from a progressively wider perspective in critical medical anthropology. At the micro level, individual experience is set within their social network located in the community, to the healthcare system interventions that are controlled by national health policy, all of which are under

the influence of historical context (Baer *et al.* 1997:28). On a macro scale the global world system of capitalism under the current market driven approaches affects the TB sufferer in New Zealand whose treatment may be managed under the WHO global policy of DOT, a normalised system that is mandatory for all countries wishing to receive aid for TB control. Explanatory models of illness evaluated without a structural context can depict the individual within a system that is free of constraint.

Critical medical anthropology represents the incorporation of a political economic perspective in interpretive medical anthropology in the belief that ways of thinking about health and illness cannot be divorced from the structural environment (local and global) from which it arises. Virchow indicated 150 years ago that health is a socially produced phenomenon and a reductionist biomedical approach alone does not illuminate the wider causes of disease (Whiteford 1996:242).

A critical perspective seeks to illuminate the underlying assumptions of attitudes to health and illness. In particular, biomedicine as the dominant paradigm in the New Zealand healthcare system, carries an inherent epistemology that is culturally informed and based on Cartesian dualisms that separate mind and body and depict the body as a machine (Helman 1990:89). Conceptions of the body as machine have been incorporated into lay understandings of the body that is made up of parts that may fail and require fixing with the aid of surgery (for example, (Helman 1990:22)). This leads to a predominant focus on the physical effects of illness without recourse to the individual as a whole human being. The sick person is then primarily defined in relation to their disease that is universally defined and consequently other contributing factors such as their lack of social support or socio-economic position and living conditions are obscured.

Conclusion

In the current study I aim to explore the experience of Pakeha with TB recognising that their illness experience rests within a broader context of their everyday lives as community members of the majority group. In order to do this patient's explanatory models need to be placed within the broader contexts with broader social, political, historical and economic trends.

CHAPTER THREE

RESEARCH PROCESS

“I’ve enjoyed talking to you because it’s been TB on the lighter side.”

What I Bring to the Study

In my choice of TB as a research topic I was attracted to the opportunity of participating in team research that is interdisciplinary. Like many other middle class, middleaged Pakeha, I was vaccinated at secondary school against TB but have otherwise since had little experience of the disease. When I worked as a nurse in a South Auckland hospital in the 1970s I was aware that there was a diminishing need for the TB ward, where people under treatment (who were often from the Pacific) had to swallow huge tablets as part of their medication. As an ancient ‘social’ disease, tuberculosis has held my curiosity as to why there has been resurgence in industrialized cities and why, if there is an efficient treatment, is one third of the world’s population infected with the tubercule bacillus? Similarly, people I spoke to about my research topic often reiterated the comment: “but I thought we didn’t have any tuberculosis in New Zealand these days.” I was therefore keen to understand the disease from the perspective of the sufferer and was fortunate to be given the opportunity to study the Pakeha perspective.

The Developing Question

I was surprised to uncover the pre-existing values that the word TB held for some people. The knowledge of a history of stigma associated with TB in this country stimulated my inquiry as to whether stigma was a continuing problem for Pakeha TB sufferers, Pakeha being the dominant cultural group in New Zealand. A report of a recent outbreak of TB in an Auckland church group highlighted the role of stigma and shame that surrounds the disease, which may delay diagnosis and result in high rates of transmission. The authors of this report called for the disease to be de-stigmatised in ethnic communities and in this I include Pakeha (Calder *et al.* 2000b:41). An understanding of stigma as it is played out

today was therefore incorporated into my research goals. The aim of this research was to examine the experience of a group who are more often omitted from research about TB and from TB in the popular imagination. investigate

Ethics approval for the study, *The Political Ecology of Tuberculosis in New Zealand – past and present* was granted by the Auckland Ethics Committee and The Research Development Office of the Auckland District Health Board that covered my facet of the study. Anonymity of participants was ensured by the use of sometimes multiple pseudonyms in my written work. Care has been taken to not use names or places that might identify them. The stigma sometimes associated with tuberculosis requires that the researcher take particular care to uphold privacy and avoid making statements that could promote the association of tuberculosis with specific groups of people, in order to avoid a second wave of blame and exclusion of sufferers that can accompany an epidemic of tuberculosis (Farmer 1992).

Meeting the participants

I conducted fieldwork in the Auckland area during the first half of 2003 with the assistance of Auckland Public Health Nurses to recruit participants who identified as Pakeha/European on their initial case report. PHNs who knew prospective participants contacted them, explained the study and invited them to participate in the research, leaving them written participant information to peruse. In discussion with the PHNs they explained that they invited all those clients whose mental capacity allowed them to give informed consent, and all were keen to help. Eight participants were recruited in this way and I contacted one through other TB networks who had completed treatment six years ago. I was also introduced to another man, while visiting the TB ward, who agreed to participate, however when I contacted him on discharge he had changed his mind because he felt that he was already having PHNs visit him at the retirement village and did not want to be further involved in research. If people were interested in participating then their PHN notified me by mail or email. After phone contact, I arranged a meeting with participants at a place and time of their choice and further explained the project and obtained written consent. Of the eight people referred to me by PHNs, all agreed to take part in interviews. One person had suffered a stroke and his speech was affected, and so I conversed with him about TB with the help of his wife.

In my fieldwork interactions I represented myself as an (obviously mature) student who was researching tuberculosis in Auckland. However, as part of the

relationship that was formed with participants I felt it important to offer other biographical details and answer questions about myself in the initial phase of establishing rapport. This was to avoid a one-way process of collecting information that can result from a formal interview process and work toward the control of the inevitable inequality of an interview relationship. Participants were given my phone number if they wanted to ask questions about the study and to withdraw from the research if they changed their mind. I did receive phone calls (and letters) from participants about treatment changes or to inform me of upcoming clinic appointments that I may have wished to attend and to arrange my help with transport.

In his discussion of the interview relationship, Bourdieu (2002) emphasises the social nature of the relationship that is inherently intrusive between researcher and participants. He advocates minimising the “symbolic violence exerted through that relationship” through a sensitivity to the interactive processes (e.g. active listening and the use of accessible language) and focused attention that offers a “total availability to the person being questioned” (Bourdieu 2002:609). If the researcher is able to bring an altruistic and generous spirit to the interaction it can validate the (illness) experience from the point of view of the participant that may not have been experienced to date. Research relationships will obviously vary depending to some extent on the personality (and age, sex or class) of the interviewer and the needs and life/illness experience of the participant. Some participants gave positive feedback positive from participating in a research process that was not purely biomedically focussed.

The participants invited to take part in the study had self-identified as New Zealand European during their hospital registration and this information was transferred to the Tuberculosis Case report that is part of national tuberculosis surveillance. Therefore participants did not self-identify as Pakeha. The nine participants in the study ranged in age from 47 to 75 years. Most were more than 56 years old and of these, four were reactivation cases. This group is not a cross-sectional sample of Pakeha with TB disease. However, from 1995 to 2002 76.4 per cent of cases of TB disease were among those aged 45 years and above. The rate of TB disease notifications among Pakeha 70 years and older was 4.9 per 100,000 in 2002, three to four times the rate for Pakeha as a whole (Sneyd and Baker 2003:75). Canadian and Australian figures show a similar prevalence of TB among the elderly in the majority population (WHO 2003:148, 198).

I am unaware that a social science approach to tuberculosis has been carried out in New Zealand to date; past emphasis has been on biomedical studies. The fieldwork

methods employed were selected to gain an understanding of tuberculosis from the point of view of the sufferer and to gauge the attitudes to health illness and tuberculosis of some people of similar attributes. I conducted semistructured in depth interviews of the nine tuberculosis participants and shorter, structured interviews with nine paired participants that did not have TB. Opportunities for participant observation occurred while accompanying TB patients on their clinic visits as well as on home visits. The views of stakeholders were gained through interviews and by attending meetings of Public Health staff in the course of facilitating contact with participants. I also visited the TB ward at Greenlane Hospital. A media analysis of television and newspaper articles collected concerning TB during the course of the study was also carried out.

Most interviews took place in participants' homes and were preceded by general conversation to establish rapport. These often followed the chronological stages of the participant's illness experience; however the normalisation of the linear perspective of illness should be treated with caution. It can reflect a cultural model of interpreting and thinking about illness that is held by the researcher. In fact on viewing each illness story in its entirety it is evident that digressions occurred naturally during these conversations to give background to events that were of significance to the participant. Therefore, the 'order' of the illness experience often became confused as the experience was recalled. In narrative theory the order and emphasis in the telling of a story can be of interpretive significance as the illness experience is being *re*-experienced each time it is retold (Bury 2001:264). I was also concerned to support the free flow of dialogue so that participants were able to highlight aspects of the illness experience that held significance for them.

Interviews were loosely structured to cover the following five questions based on Kleinman's (1980) explanatory model of illness:

- What do you think has caused your problem?
- Why do you think it started when it did?
- What are the main problems your illness caused you?
- What do your friends and family think about your illness?
- What do you tell people about you illness?

(Kelly 1999:236)

All but one of the participants agreed to the interviews being taped. Tape-recording allowed me to focus on the free flow of conversation without recourse to detailed note-taking. On completing each interview I made notes about the setting and context of the interview. Following the recommendations of Emerson (1995), I kept a book of jottings

that I often wrote up immediately after leaving the interview. I was surprised at the concentration required at interviews and I found free writing about the meeting helpful during a break. Emerson (1995:12) holds that the emotional reactions that the fieldworker experiences are an inevitable element of fieldwork should be divided up into 'objective' and 'subjective' categories. Therefore they need not be recorded in different places because fieldwork is always interpretive. Each interview was transcribed verbatim as soon as possible after the interview. The activity of transcribing the conversations as the interviews progressed forced me to confront and refine my interviewing skills during the fieldwork process. I took a *koha* (offering) of fruit or preserves to each participant when I met with them for the interview.

Some participants took up the offer of receiving a copy of the transcript which was sent with an accompanying letter and followed up with a phone call to allow discussion and elaboration of the interview as necessary. Elderly people, in particular those with earlier experiences of tuberculosis, took pleasure in sharing details of early life not previously discussed with family, through reading the transcripts. Follow up after returning the transcripts and my accompanying participants to clinic appointments provided opportunities for repeated contact, dialogue and participant observation that fleshed out the initial interviews. Although only the initial interview was tape recorded, in all cases, I made notes about the details of each interaction.

The Chest Clinic at Greenlane hospital and the Infectious Disease Clinic at Auckland hospital are sites where most outpatient follow up takes place and I was able to provide transport and share the visits with participants on five occasions (after requesting medical permission). This was a relaxed and worthwhile interaction on each visit and went some way toward offering some reciprocity for their willingness to help me with my research. When this was possible it offered an opportunity to extend the 'interview relationship' and develop mutual rapport that can lead to the participant sharing their "private account" (Cornwell 1984) of their illness experience. I am very aware that the long-term relationship that public health nurses develop with their clients would challenge the depth and breadth of understanding about participants that I have achieved in this short study. However as key players in treatment they have a different relationship with participants to mine. I did not discuss my participants with the health professionals who knew them after the initial written or oral introductions were made.

I was also exposed to the experience of professionals involved in TB treatment by visiting the TB ward at Greenlane hospital for half a day where I joined the doctors' round

and spoke with patients, nursing staff and visiting public health nurses involved with tuberculosis treatment and follow-up in the community.

Ideally the fieldwork would have also involved members of the social networks of TB sufferer, particularly other household members. This was not carried out due to consent not being granted on two occasions (perhaps due to tensions in the relationships that were inflated by TB) by network members. This may also have been due to the fact that many participants lived alone and relied more or less on a variety of social or professional support networks for help during their illness. An alternative strategy was set up to broaden the study of Pakeha attitudes to TB and it took the form of paired interviews with community members (who did not suffer from TB) that matched the status (age, sex, occupation) of the nine TB participants as closely as was possible.

The paired interviews were shorter than the TB interviews and followed a more structured approach about attitudes to health and illness and tuberculosis disease. The questions about health and illness were modelled on those of Chambers and Macdonald (1987) whose study was based on research with middleclass Pakeha women. This study has also been the basis of research questions in theses by Koops (1996) and O'Connor (O'Connor 2000), and the consistency of approach provides opportunities for comparisons to be made. Recruiting participants for this aspect of the study was surprisingly difficult. I was to learn that 'cold' self introductions by researchers are treated warily by older people. My personal visits to pensioner flats were fruitless despite having the opportunity to explain my request with several individuals, many of whom commented that they "wouldn't know enough" (i.e. that is, about health, illness, and TB). In her study *Hard Earned Lives* by Jocelyn Cornwell (1984), found that a reluctance to talk about health was common, in fact often "they changed their minds and tried to back out; sometimes they refused, insisting that there was 'no need' for them to be included in the study because their health was good, and it would be better to ask someone else..." I found people very willing to participate in interviews if the request was made via a go between from my own social network so that often the response was couched in terms of helping the student complete their research. These interviews also took place in the homes or workplaces of participants and lasted about half an hour. It was noticeable that participants often appeared apprehensive in the more structured type of interview questions, possibly due to the reduced time spent establishing rapport and a concern with giving the 'right' answer reflecting a concern with stating a "morally correct position in relation to them(selves)" (Cornell 1984:123). During these interviews I felt the need to constantly reassure

participants that there was no 'right' answer, that I was interested in their opinions or ideas in response to the questions.

Apart from these matched interviews, many people in the community learning of my study proffered stories and opinions regarding TB. Those over 60 years usually had some knowledge and personal narrative about TB as part of growing up in post-World War Two years and some showed their interest to the extent that they sent newspaper clippings about TB. Existing TB surveillance data was collected about national and Auckland TB disease case notifications. All participants gave written permission for me to view their hospital and PHN case notes.

The analysis of interviews may subtly begin during the interview. After fieldwork was complete I read the transcriptions as a whole and reread carefully to identify themes or categories in a process of open coding as suggested by Emerson (1995:143). In my analysis I attempted to maintain a reflexive approach and to acknowledge my position as writer so that in constructing my interpretation, I remained as close as possible to everyday life of the sufferer. In this way the field notes can 'speak' to the researcher to suggest themes that are not preestablished (Emerson *et al.* 1995:152). A set of core themes were subsequently established and manually indexed. Gradually the importance of various themes developed in relation to each other, a process that continued to develop during the writing phase. On occasions I was able to further clarify questions that arose by maintaining telephone contact with participants.

I now follow with the results of my research.

CHAPTER FOUR

BEING HEALTHY, BECOMING ILL

“I’ve got a strong constitution, [that’s] the reason I kept going as long as I did”.

Ways of thinking about health are situational and do not exist in isolation. They permeate many aspects of daily life, serve as a basis for interpreting bodily changes associated with illness, and influence actions taken to maintain or achieve health. Health and illness theories for Pakeha are not homogenous because they are affected by a myriad of factors such as social and economic resources, personal experience, gender, age, cultural norms, education, and the environment. Perceptions of health and illness underlie the actions taken toward managing health maintenance and treatment-seeking in times of illness (Crawford 1985). Therefore an overview of Pakeha health cultures provides a background to understand illness meanings and how they impinge on decisions people make when they develop tuberculosis disease. Health cultures are comprised of the knowledge and understandings that are acquired over time in local interactions with social network members about the nature of health problems and likely outcomes (Rubel, Garro 1992:627). They are employed by sick people and their caregivers to manage illness episodes using available therapeutic services in the context of socio-economic and geographical constraints (Vecchiato 1997:185).

In this chapter, the results of the paired interviews concerning perceptions of health and illness of non-tubercular Pakeha participants are reviewed to gain an overview of health cultures among older Pakeha. The second part relates the paired interview outcomes to the transitional illness experiences of Pakeha tuberculosis sufferers in this study and moves chronologically through the help-seeking process toward the eventual, yet in some cases delayed, TB diagnosis.

Being Healthy

Paired Interviews

The meanings of health for individuals are complex and dynamic; they are incorporated in everyday living and not often consciously expressed. This contributed to the hesitation and difficulty that some participants had in talking about the meanings health held for them.

In the paired interviews I talked with nine Pakeha people, aged between 49 and 73 years, who did not have tuberculosis about their perceptions of health, illness and tuberculosis. I asked about the meaning that the word 'health' held for these participants. Communicating this was difficult for some. One man (aged 52 years) was defensive and blamed his reaction on my question that he found "weird, strange" and "a bit vague"; he said that "health did not mean anything to [him] really".

When I realised that some participants felt 'put on the spot' by the open-ended question about which they had rarely thought, I altered the order of questions in subsequent interviews. The meaning of health for participants was often expanded later in the conversations about health maintenance and illness.

The Meaning of Health

In describing the meaning of health, three participants aged between 70 and 73 years expressed notions of being fit and unrestricted in their daily activities by pain, sickness, or "a sore foot". I have loosely termed this a 'functional' explanation of the meaning of health. These elderly participants also spoke of physical impairments that they worked hard to overcome through specific exercise or dietary management. Being able "to do what you want to do", as defining the mainstay of health was the prime functional explanation. In her study of Scottish working class women, Blaxter (2000b) also noted that elderly people were more likely to define health in relation to functional abilities and she suggested this was due to the tendency for younger people to take their physical body for granted.

Four participants aged 49-60 years viewed health from a more 'holistic' perspective that involved physical, emotional and spiritual aspects, often described in terms of balance or vitality. For a man of 52 years, health meant:

to live and to feel good, to be happy and enjoyable, I think it is a holistic thing rather than just a medical, "what's your body doing?"

Interestingly all of those who held holistic ideas of health lived with few restrictive ailments and were 10-15 years younger than the functional group. Stages in the life-course and possibly cohort effects affected the meaning of health for these Pakeha participants. Gender did not appear to determine attitudes in this sample and there are suggestions of this in other studies (see, for example Chambers and MacDonald 1987). The body was closely allied with health meanings for all, whether implicitly when health centred on “the ability to carry out normal tasks without any suffering or pain” or explicitly, as in “wellness ... it means being fit”.

These findings about the meaning of health show similarities with other age and gender specific health studies carried out locally. The following studies all based their questioning on the model provided by Chambers and MacDonald (1987) whose study focussed on middle-class Pakeha women aged 30-46 years, and whose ages today roughly correlate with the younger paired participant group. Findings showed that more than half of Chambers and MacDonald’s participants viewed health as a multifaceted interaction of mind and body as does this study’s younger ‘holistic’ participants. This also concurs with Vaughn Koops’ (1996) study of middle-class Aucklanders aged 21-31 years who found that all of his participants perceived health as mental and physical well-being. Furthermore, O’Connor’s (2000) analysis of conceptions of health for middle-class men aged 15-24 years in Auckland revealed some holistic views of health with particular importance placed on physical fitness. The age-related variation in concepts of health found here demonstrates that health “is in a constant state of flux and is subject to changing social and political realities” (Davis and Dew 2002:14), as well as biological realities.

For these people everyday activities are lived and expressed through bodily experiences that are central to health generally. The meaning of health was often enlarged upon during the general conversations about health and illness.

The Meaning of Illness

Two people initially described the meaning of health in utilitarian terms but later related meanings for illness as being an impairment of mental, physical or spiritual elements. For some, illness meant the inverse of health: “a lack of wellness”, or as one person indicated, loss of income. Illness had a nuisance value which necessitated that participants “act accordingly” whether that was to “slow down or go to bed” or to just “flop around miserably”. Four participants referred to the mental effects of feeling ill, whether in terms of “feeling depressed”, or “like a sad sack”. The metaphors that illness conjured up

indicated a sense of loss, whether that be of productivity, or of physical and mental wellness.

Health Responsibility

All participants felt that the individual and then, their family were primarily responsible for their health. This was further elaborated by the expectations that people must exercise (mentioned six times), attend to their diet (mentioned five times) and be motivated (mentioned three times) in order to become or stay healthy. This result was also reflected in Chamber and MacDonald's (1987:25) study with the same order of emphasis. Although at the outset of these interviews, participants sometimes spoke about the meaning of health as subconscious, in contradiction, most related health to intentional, purposeful practices. In short, to attain health people have to "work at it" because responsibility for health lies actively with the individual. This result was also reflected in the work of Staltonstall (1993) who interviewed white, middle-class Americans aged 35 to 55 of mixed gender.

Health promotion or education has long been a state responsibility as reflected in the goals of the Department of Health in the 1950s: "The promotion of healthy living then, is our first aim. This is done by education, propaganda and a little bit of force" (Wallace 1953:3 cited in Hyde 1999:256). The 'new' public health was outlined in the World Health Organisation document, the Ottawa Charter for Health Promotion of 1986 and encouraged the promotion of self responsibility in healthy decision-making of lifestyle choices. The influence of WHO, associated with neo-liberal reform, led New Zealand public policy to increasingly advocate individual self-regulation measures toward preventative health and it appears the public have taken up the suggestion wholeheartedly (Hyde 2002:257, Reid 1999:92). A recent example is reflected in government policy to stop smoking and publicise concern about juvenile obesity and sedentary living.

Two men (aged in their 70s) talked of the responsibility of their wives to "be up every morning and cook the kids a substantive [sic] breakfast". Another spoke of his wife's responsibility to cook at least seven vegetables a night as part of women's responsibilities for family health. Gendered responsibilities in the health cultures of Pakeha tend to place women as health-keepers or managers of family health (Chambers and MacDonald 1987). Wives who are accountable for food preparation also manage health as well and yet moral responsibility for their work is taken by their husbands.

Behaviour modification or lifestyle choices clearly form part of preventative health management and are considered a personal responsibility in keeping with the current

emphases in public health education. However, in asserting that lifestyle changes can produce good health there is of course a presumption that people have the power and resources to make changes, for example being able to afford fresh food in obesity prevention (Pill and Stott 1982). Virtuous management of diet is an essential activity toward health. According to this man (aged 73years):

I have always believed in seven vegetables a night...my wife tries for ten. That is common knowledge, I thought.

Crawford (1994:1353) holds that a new health consciousness has been prevalent in middle-class America since the mid 1970s so that: “health can be understood as a metaphor for self-control, self discipline, self denial and will power”. People have a moral duty to stay well. There are aspects of self-responsibility and restraint present in the following:

You have to put the effort into it, you don't stay healthy just by wishing, get out and do something about it. (73 year old man)

Self care was first really, you've got to look after yourself really, not the next person, self care, watching diet ... choosing the right foods to eat. Everything has got to be in balance, walking, exercise, activities. (60 year old woman)

The best thing for people to stay healthy is to watch what their diet consists of and ... leading a healthy lifestyle such as keeping fit as much as possible. (56 year old man)

Health does not just happen, it is not static and as an active, disciplinary process it must be managed. The above comments reflect “a duty to be healthy” (Pierret 1995:181) that reinforces assumptions that the individual is responsible for health. However, people do become ill and in the light of these prescriptions for health, I now consider paired participants' accounts of illness causation.

Causes of illness

Participants had multiple explanations of illness causation. Of nine participants, six put the locus of blame for illness on individual behaviour such as bad hygiene, eating the wrong foods, smoking, being overweight, lack of exercise or used a cultural deficit model (for example, “some cultures don't take care of themselves properly”). I have included overwork in this behavioural category. The germ theory of disease was expressed as “you can pick up a bug” (i.e. from without) or you “can't dodge the germs” expressed by four participants in varying ways. Environmental causes such as sprays were mentioned by two people one of whom had worked in a war zone. Genetic causes of illness were mentioned

twice and illness as a social product was indicated once. Another said, “that’s self-explanatory I thought, you know what causes everything”. He refused to be drawn further on it but in the context of the interview it is probable that his thinking derived from a scientific model.

A large study concerning the attitudes of elderly people to the causation of specific diseases (heart disease, cancer, tuberculosis) in the Republic of Ireland found that participants cited multiple causes for each disease (MacFarlane and Kelleher 2002). The authors similarly noted that behavioural explanations for disease predominated, with few references to social causes of illness, in keeping with biomedical health models and the public health education emphasis on lifestyle modification. Elderly people were also likely to have witnessed increasing standards of living over a lifetime that affects their perceptions of socio-economic status (MacFarlane and Kelleher 2002:1399). Another explanation may be, as Blaxter (1997) suggests, that enquiries about participants’ attitudes to health and illness engender responses that elaborate their social identity and those who experience social inequality are reluctant to label and devalue themselves in the process. For example, an unemployed TB participant noted the cause of his illness to be behavioural or work related despite the fact that he had not had work for some time and had poor nutrition and living conditions. However he emphasised his work history and personal habits (e.g. smoking) as possible causes rather than reveal his present low social position as causing his ill-health. Responses in Blaxter’s study varied by social class in that “it was those in the more favourable circumstances who were more likely to appear to think in economic or environmental terms” (Blaxter 1997:748). She related this to the moral imperative to be healthy in Western Society that discourages marginalised people from exposing their “risk status” (Blaxter 1997:756).

In summary, I found that the most frequently mentioned cause of illness was behavioural, with equal emphasis on microbial, environmental and genetic causes.

Responses varied, however, when results about illness aetiology were compared with those in response to the similar question I asked concerning whether some people were more susceptible to illness than others. Among the answers, I discerned groups of underlying themes that were environmental (including stress, poor living conditions, occupation, pollution), genetic (inside the body but outside control), behavioural (smoking, fitness, alcohol), and luck. These numbered six, five, four and two respectively. So while participants recognised external causes relating to social inequality for others’ illnesses, they did not when talking of their own experience.

In a study of illness in London, Helman (1990:104) found that illnesses that arise from within the body usually carry connotations of blame on the individual due to a failure to take adequate care of diet, exercise, hygiene, relationships, lifestyle, clothing, drinking and smoking. Although ‘germs’ or ‘bugs’ are generally unseen entities they now contribute to beliefs about illness causation that have been taken on by the public in industrialised countries from biomedical microbial theory. This has influenced the treatment deemed necessary for the sufferers of colds and fevers since the Second World War. Subsequently the younger ‘antibiotic generation’ are more prone to seek medical help for ailments that were once dealt with in the home due to a shift in the perceived causes to outside entities, i.e. germs. These ways of thinking about illness may be in tension with the new public health promotion of individual responsibility for health (Helman 1990, Pill and Stott 1982:49). The bacillus that causes tuberculosis may be seen as an outside cause by those who go with the germ theory but in another sense, because it is an infectious disease and tuberculosis may be caught from close associates, it also has a social cause. Blame can be laid on ‘other’ people who brought it or ‘gave’ it to the sufferer because of their carelessness or perceived traits. Helman (1990:109) makes a correlation between this practice of blaming others for infection and accusations of witchcraft in some societies. This raises a possible connection between stigma and the ‘diseased other’ that reflect community attitudes to TB (to be discussed in chapter 6).

These understandings of health and illness provide a background against which the corresponding understandings of participants who experienced TB disease can be contextualised. The recent concentration on treatment compliance has led to social science studies about TB that give behavioural explanations for non-compliance (for example Mata 1985:62). The resulting studies have sought to predict compliance in relation to perceived causes of TB and they display a variable relationship between causal understandings and compliance with medication regimens. Farmer (1997:351) shows that TB sufferers in Haiti who thought their illness was caused by sorcery were adherent to TB chemotherapy when traced over a period of eighteen months. The main influence on compliance there was access to adequate food and income. Farmer (1997:353) cautions that research that stresses the causal role of culture in unsuccessful treatment is in danger of “conflating cultural (or psychological) difference with structural violence”. As part of explanatory models, perceived causal factors of illness are useful in promoting an understanding and respect of differences in the approaches to specific illnesses in healthcare settings.

Becoming Ill

“I got more and more tired and just sort of stiffer and creakier”.

How Did You Know You Were Ill?

Helman's (1995:56) research has shown that a large proportion of illnesses are treated without recourse to medical consultation. The first signs of illness may prompt an ill person to try a variety of remedies or advice based on a local rationale of the body in health and illness that may or may not eventually necessitate recourse to medical professionals (Helman 1990:18).

One recent study found that people are unlikely to reveal their 'hierarchies of resort' that involve self treatment to a biomedical professional not only because they feel uncomfortable about the perceived legitimacy of their actions, but also because of the unlikelihood of an expression of interest from the practitioner (Stevenson *et al.* 2003:521). Members of the social network of the sufferer are often aware of their feelings of dis-ease and may give advice, support or stand-in for everyday roles that the sufferer is unable to carry out. This is shown in Frank's story below when his friends urged him to go and get a test. Their diagnosis added to the several options that Frank constructed for himself.

Alternative therapies or over the counter remedies may be tried, or voluntary behaviour changes may be made that relieve symptoms. An increase in rest and stopping smoking were commonly resorted to by the TB participants in this study in an effort to abate early troubling symptoms of tuberculosis. I was unable to elicit instances of resort to 'alternative' therapy from these TB sufferers but it has been detailed in overseas studies of tuberculosis.

Illness narratives are able to capture the stages of illness acknowledgment that often exist outside the biomedical diagnostic explanations of tuberculosis especially in the early stages as indistinct illness patterns emerge. Since diagnostic delay is a concern in tuberculosis control (due to increased disease levels for the sufferer and the spread of infection) I will elaborate this phase of tuberculosis illness that is rarely portrayed in detail in case notes. The following narrative illustrates the protracted period of uncertainty that accompanies the insidious development of tuberculosis which initially mimics other common maladies. For this reason, doctor's visits often do not immediately reveal the

source of the problem as a doctor must first suspect TB and carry out specific tests to achieve diagnosis.

It is clear that for Frank (a 46 year old professional), his conception of health is not merely physical, it has mental and spiritual and social relations and this is borne out in his discussion of the range of experiences that he brings to the discussion of his ailing body. The cause of his illness is not singular for Frank, although at the time of telling this story he was aware of the causative organism of tuberculosis. He is answering the question often asked, “why me, why now?”

The narrative in retrospect (he completed treatment 6 years ago) provides Frank with an opportunity to express and work through this frightening time by revisiting it on his terms, by his own design. The cause is likely to have been shortened or selectively edited (by him or the practitioner) in a biomedical consultation. As (Cornwell 1984:148) found, people frequently have public and private accounts or theories of illness causation. A public account is more likely to conform to the medical point of view and be ‘trotted out’ in situations that demand a medically legitimate account. I suggest that Frank is here elaborating his private theory of illness causation as he experienced it, embodied in his life history.

Frank's Story

“I couldn't even make the bed”

Frank: Now what happened then, in sequence ... I'm actually very fit, I jog a lot, I did jog a lot then, I now go to the gym. In early 1996 I started feeling extraordinarily tired, I think that last time I jogged was about February 1996 and a couple of my friends noticed that I was losing weight and they said, “are you okay?” I said “yeah, I'm fine, I'm fine”, but I know I was getting tired, I was just getting too tired to jog. Now, at that time there were a few things, I'm gay, I had a friend who was dying of AIDS, not a lover, a friend. He was dying of AIDS, and I was really the person closest to him, actually, when I say looking after him, I was there for him, helping him, financially and otherwise, I would visit him every day or keep in touch. There was a stress there, he actually died in March 1996, so there was a stress there for me, and it was very busy here at work. It was a particularly stressful time for various reasons here at the office, I was finding that hard so I think I just got run down.

Alison: Grief is something that I am finding from talking with other people, it coincides quite often with the onset.

Frank: Yes I think there is something in there that let my defences down. I was also struggling then with a personal relationship. So all in all I had lots happening, and I was ... yeah, I think that's what actually happened,

that's what I believe, for those reasons my defences were down and somehow it came through and I didn't realise.

Alison: No, you wouldn't.

Frank: So that's what was going on and then progressively, February, March, I'm feeling tired, strange ... And then there was a virus going around, now K. died in March, we buried him, sometime later, now when was Easter that year? I recall Easter must have been March, early April, I recall over Easter I felt absolutely miserable, I really felt sick and I thought, I'm just tired and I didn't come right over Easter, that's strange ...

Alison: You rested up over Easter?

Frank: Yes, I rested up and I went to see the doctor and I said, he said, "well maybe you've got this virus that's going around, what ever is lingering, a sort of a 2 week type thing. Do you want blood tests?" And I said "no, it'll pass, blood tests! I'll be fine, it'll pass," but it didn't pass, I gradually was getting more and more tired and I recall, that was March, I sort of put up with it through April, and I recall my niece's birthday. My youngest niece's birthday is 30th of May and I was at her parent's place for a birthday lunch, she was a little tot she was 3 or 4 years, 3 years old then, I recall sitting around thinking, "I feel sick there's something wrong, no nothing, maybe I'm just depressed". I thought of other things that were happening and I thought, "well that's what it is you know". And then a couple of weeks later, I live alone, I was making my bed and I ran out of breath making my bed and I thought "no, this is too much, there is something else wrong here".

And that's what triggered it, I went and saw the doctor immediately that day and we had a chat about it, he took my blood pressure and said "Oh 98, not my blood pressure, my heartbeat, pulse", he said "11 o'clock in the morning, far too high" given my history which was good health, strong person, no real problems, so he sent me off immediately ... they x-rayed my chest. They sent me back to my doctor who is a fine doctor, a very sympathetic person and he explained to me that my left lung was 2 thirds full of fluid and he explained that this meant anything from a nasty infection through to cancer. I said "well it's not cancer", he said "well how do you know?" I said "well I'd be in pain", he said "you can't assume that". ... And so the doctor discussed this with me and said "we want you into hospital immediately".

Early in the interview Frank had talked with pride of the level of fitness he usually maintained, in part through jogging regularly with his friends. Frank chose to open his illness narrative by setting the record straight that he is not careless about health maintenance. He works at his health; he takes responsibility for it, for this is a desirable facet of citizenship in the age of the 'new' public health that requires self surveillance and regulation of the self to achieve health. It is interesting that his incapacitation is portrayed

initially in terms of coping with a health maintenance activity (jogging) and the final straw is not even being able to perform a domestic task (making the bed). The levels of energy and desirability and stress of these activities are culturally influenced as are the evaluations of “bodily and emotional states, determining whether they will be evaluated as stressful or not” (Kleinman 1980:79).

As Frank contextualised his feelings of sickness and tiredness amidst his recent life events he made a diagnosis of depression that did not satisfy him amid the intensified disruption of his symptoms. This personal diagnosis of mental illness alone did not instigate medical help. Instead, it is regarded by Frank as a causal factor of tuberculosis, his feeling “down” is related here by Frank (and others, as will be elaborated), as a form of stress that allowed the TB within the boundaries of his healthy self (Crawford 1994).

Frank recalls the uncertainty surrounding the early phase of illness. He described how a person may go in and out of denial, in response to an increasing intrusion of the effects of illness on the body that increasingly threatens normal everyday activities. Similarly a paired interview participant spoke about his fear of becoming ill. He was reluctant to take on a ‘sick role’; perhaps due to the inference that an aging, weakening, body would affect his identity when he had earlier defined health as vitality.

... it’s scary I guess, but um I don’t even like admitting I am ill when I am ill, I would rather people see me as being healthy and bullet proof, like a teenager! (56 year old man)

Ill health brings a threat to self-control and identity and if health is considered a central part of identity, as Crawford’s (1994:1355) study found, it is not surprising that it is accompanied by denial. Having TB has caused a negation of the “healthy self” (Crawford 1994:1348)

Time played an important role in the lead up to Frank’s eventual diagnosis. Over time his symptoms worsened and his ability to cope with everyday living diminished. His initial trip to the doctor allayed his fears and he was comforted and reassured by the thought that it was a transient illness ‘going around’. His presentation to the doctor did not spark concerns of TB at that stage. He is able to recall important key dates that have taken on added meaning in the context of the illness narrative. His niece’s birthday marks an overwhelming feeling of sickness that was confirmed as disease shortly after. His narrative has several minor crescendos that can only be so in hindsight. “Making the bed” became a final turning point toward his repeated pursuit of a diagnosis and reluctantly accepting a sick role. His preconceptions of cancer as a painful disease served to convince him

(although not the doctor) that it was not a possibility. The overwhelming lethargy and mystery of the early illness phase led other participants to suspect that they had cancer, a theme to which I will later return. Most participants recalled a loss of control of their body as the disease took over their life.

When It All Goes Wrong

The previous scenario of early illness uncertainty and denial was also true for Debbie. Her Pacific Island holiday experience was disrupted by feelings of shame and lack of control caused by suffering from symptoms of an illness for which she had no name. Debbie had booked her holiday to recuperate from joint surgery and to celebrate her daughter's 30th birthday, but things went terribly wrong.

Curiously enough the morning that we flew out which was 4 o'clock on Sunday morning at the airport, I *absolutely* burnt up, my face was just burning and I put it down to excitement. It was absolutely terrible, it was an uncontrollable feeling. ... I couldn't walk, I went to sleep on the beach, I did loud snoring, I couldn't shop, I was in absolute pain and yet I didn't know what was wrong ... I had no idea ... my body ached to bits.

Notwithstanding this, on returning to New Zealand Debbie tried desperately to convince herself and the doctor, that things were not that bad.

He asked me how I was and I said "fine", and he said, "well you're *not*", and I thought "well I wasn't really", but I felt that you know it's nice to ... You try to be pleasant and happy when you see these people.

Despite visiting the doctor for help with health matters, she tried in vain to present herself as polite and in control at the same time seeking legitimation of her suffering. Debbie accepts and reinforces the power differential in this medical consultation by attempting to present herself in a socially acceptable light.

Similarly, Diane explained away her feelings of being unwell as being part of the aging process. She is a TB survivor of times past and she wanted to get on with issues that were more important to her, such as helping her sick daughter.

... I didn't feel really sick, I was off colour, I knew I was off colour, but you know, I'm nearly 74 so I mean, you've got to expect to be a bit off colour don't you?

As these people show, uncertainty and denial are strong themes in their early illness experience. There is a wish to go back to activities that denote everyday certainty.

The prolonged denial that Frank (46 years) acted out brought a strong reaction from his mother who did not have patience with his attempt to convince himself and his friends that he was really all right and that he could “carry on as normal”. Prior to his diagnosis, after a diagnostic procedure, he recalled:

I was in hospital in some pain, they sent me home the following day, ... and big silly me decided I wasn't really sick after all and I recall cooking dinner for some people that night at which my mother had a purple fit and said “you shouldn't be hosting dinner parties at all”. Here I was being tough, I just sort of carry on.

This had been articulated earlier in the interview by Frank when he identified with a history of “good health” and being “a strong person”. A fear of being viewed as lazy or malingering drove Debbie, Diane and Frank to forgo a performance of suffering in favour of presenting to friends and the medical profession as uncomplaining. **The uncertainty prior to diagnosis may be replaced by a relief of legitimation after ‘it’ (the disease) is named.**

When individuals are believed to be responsible for their health through behavioural management of fitness levels, diet and motivation, then it follows that when health is threatened, the locus of blame comes back on the individual who has in some way failed. If the causes of illness are derived from an ideology of ‘not looking after yourself properly’ then it is unsurprising that sufferers feel the need to put on a ‘brave face’ and acted out a denial of their sickness to preserve their identity and moral integrity.

As I have stated earlier, whether an illness is believed to be beyond the control of the individual or not is connected to the causes associated with it (see also Calnan 1987:57).

What Caused your Problem?

In contrast to biomedical conceptions of illness, for the sufferer, the illness is rarely mono-causal. Herzlich (1987:98) found that a microbe was often not a complete explanation for illness because sickness raised “questions and interpretations that went beyond the body itself”. Therefore lay illness etiologies are invariably multi-causal, with numerous causes acting simultaneously (Helman 1995: 110).

Reflecting Back on ‘First Time’ TB

Two women with reactivation tuberculosis recalled the poor rural living conditions of their childhood as a possible cause of their first experience of TB illness.

Might have been the poor food or something I don't know. ...The only thing we were short of most of the time was food. (Rose 75years)

Our home was in a rural valley, it was very damp and foggy, so much so that 3 foot icicles would hang from the veranda and last all day if the sun did not get to them. When my mother was taken to hospital by ambulance with TB it was so damp that my father could squeeze water out of the mattress. (Diane 74 years)

The relative poverty experienced by these women amidst conditions of endemic tuberculosis during World War Two gives some insight into their rural living conditions. This era was at the time that preceded urban migration and the period of renewal in the 1950s when the rate of tuberculosis cases in New Zealand fell sharply. Structural causes are further illustrated by Dennis, another TB elder who offered contextual insight into changing treatments and social conditions.

When I had it earlier 94 per cent of the population had been in contact with it. A Mantoux can tell you whether you've come in contact with the germ. The Mantoux testing is not done now and so they wouldn't know.

People get it if they are living in close proximity when one of them contacts it, bad housing conditions. It hit the Maori pretty hard. 50 per cent in there were Maori due to living in close proximity in poor housing conditions. You can build up a resistance to it; if you don't come in to contact you can't build a resistance to it. To keep a resistance you've got to be well fed. A hellava lot of kids nowadays don't get well fed so their resistance is not good. With unemployment and poverty it was inevitable that TB would come back.

Imagine the money the government put in for sanatoriums all over the country, TB wards in every hospital, x-rays for all in hospital, mobile x-rays in businesses and schools, vaccinations. They got rid of it and followed up with good housing and employment ... Now the only reason the government does something is if *they're* liable to get it.

This punchy, historical, biomedically informed, political economic analysis of TB comes from personal experience of two tuberculosis episodes. The experience encompassed two distinct eras of extensive social security provision of healthcare versus health after neo-liberal reform and it leaves little unsaid. In his astute knowledge of TB as a social disease, Dennis dodged implicating his personal social conditions, portraying his original cause of illness as "working too hard". His reluctance to identify himself in the social scale further substantiates Blaxter's (1997) claim that revealing personal unequal status involves a devaluation of the self. Dennis' ability to depict the 'big picture' of TB was unusual in the people I met in this study but it also served to distract from his feelings

about being vulnerable and sick. As a 21 year old he spent two years in a sanatorium with tuberculosis. He was only visited twice by his family at his own request because it made it 'too hard' otherwise and he continued the practice of self imposed isolation during recent episodes of hospitalisation.

Most participants' accounts of the cause of the illness dwelled much closer to their personal local world. They often spoke of other personal predisposing factors or events in their lives that allowed them to become ill, by lowering their resistance. 'Health as a reserve' was first explained by Herzlich (1973) in connection with her study of middle-class men and women in Paris. A reserve of health refers to "a capital asset of vitality and defence" that may fluctuate "in the course of time, like any capital ... Childhood is a period especially favourable to developing a good reserve of health" (Herzlich 1973:57). Similarly, Dennis described diet as a kind of 'banking system' that contributed to a reserve of health when he spoke of needing to be "well fed" to "keep a resistance". Another elderly man had similar ideas but where children were concerned he granted responsibility to the government: "I do think the government or somebody of this country have got to concentrate more on child health. If they do that then they won't get sick when they are older". Akin to balance, equilibrium is to be strived for; it is reached during periods of vitality and full reserves of health but does not exist in half measures. As an ideal, equilibrium is characterised by holistic wellbeing, it is more than the physical (Herzlich 1973:58-61). Equilibrium is a key symbol of health but like health itself it is a subjective state, varying between individuals. In his severe debilitation with TB illness, Dale explained that he has a "strong constitution, the reason I kept going for as long as I did". A sense of loss or guilt may accompany loss of health during illness. There are obvious similarities between notions of a good constitution or a healthy immune system, all of which can be compromised by stressful events that were commonly cited when participants looked back on the pre-illness phase. Metaphors such as 'feeling down', 'being run down' as a result of grief (over the loss of a relationship or of a loved one) or physical stress (such as overwork or under-nutrition) explain the depletion of the reserve or resistance of the immune system.

... well I was down, because I looked after my Dad [who was dying of cancer] and I suppose that was the hardest thing I ever done in my life, you know 24 hours a day, and I didn't have any help ... and then my lady left me ... so yeah I had a few, I was down ... So that's what they say, if your immune system is down, or you're run down or not eating properly ...

The pervasive discourse of the immune system that upholds the body as a complex system in “delicate relationship to its environment” is a central concern for Emily Martin (2000:123) in her study of the conceptions of health for ‘well’ Americans in Baltimore. The inner immune system adapts defences to contend with dangers lurking in the environment inside and outside the body. As the realm of causation in health widens, then so too do realms of responsibility, so the mere regulation of diet and exercise by individuals, in order to affect health, can only be partial. Wider relationships within the environment are also implicated in health maintenance. Accordingly, in the search for a cause of illness, TB participants cited multiple stressors in their lives that they felt were responsible for their inability to deflect the TB bacillus.

Earlier in this chapter I cited Frank, who said that his “defences were down and that’s how it came through”, as a depiction of outside forces gaining access to the body. Popular publications between the 1940s and 1970s had used the metaphor of the body as a castle with an emphasis at that time on repelling threats outside the body by sanitation measures. Attention shifted away from disinfection to portraying successive lines of defence (such as antibodies) located inside the castle (the body) that are specifically honed to deal with the myriad dangers the body can no longer reliably keep out (Martin 2000:127). Interestingly, Frank, Ernie, Diane and David, clearly consider mental wellbeing to be an essential part of their pre-requisite defence. Martin (2000:131), (in reference to AIDS) makes the point that the responsibilities and controls (of stresses) that the individual must shoulder to maintain their health according to this paradigm are so far reaching as to induce a feeling of powerlessness to “ fix everything ... if I can’t I will die from this disease”. In order to create meaning out of the illness experience participants pondered on diverse causes of their illness, often connecting their TB to emotional upheavals in their lives. These linkages have implications toward reaching a sense of feeling healed.

Despite the tendency for ‘healthy’ paired participants to blame illness on unhealthy lifestyle choices including drinking too much and smoking, it was unusual for TB participants to do so. Most people cited contributing causes that they felt were not in their immediate control, although many also imbibed alcohol and smoked.

For Diane, (who has a terminally ill daughter):

...of course worrying about her has got me down obviously. I’m a mother I don’t ever forget it, you know, it’s sort of in my mind all the time ...

And for David:

I assume my immune system was compromised through work stress, um or depression or what ever ... I had a lot of stressful deadlines and meetings and stuff like that.

Similarly for Dennis:

“I was working too hard as a plumber drainlayer 7 days a week”

Participants displayed a need to fit the resulting tuberculosis into their life history in a way that explained the contradictions of life. They based their illness causation on behavioural and occupational explanations in conjunction with biomedically informed reasoning, the combination of which serve as their explanatory models.

Explanatory Models

As noted in Chapter Two, explanatory models are a useful way of understanding the disease from the point of view of the sufferer. Explanatory models are culturally informed, dynamic, and adjust to accommodate personal experience and the ideas of a person's social network to account for the experience of illness. Most Pakeha I talked with were inevitably influenced by the biomedical paradigm.

“In the USA and other technologically advanced Western societies, lay accounts of sickness (especially those of the educated middle-class) not infrequently are heavily influenced by the biomedical paradigm, and consequently more and more a disease orientation is incorporated into illness models in the popular sector of their health care systems”.
(Kleinman 1980:74)

After a diagnosis of TB was made, the patient's treatment was accompanied by education into the biomedical perceptions of the TB disease process (the biomedical explanatory model of TB). Thus the explanatory models that follow have been influenced by their personal experience of TB disease and biomedical explanatory models. This is evident in the details offered about the causes and problems which reflect greater expertise of TB disease than in the paired participants' views. The adage, 'experience is the best teacher' certainly rings true for expanding on the meaning of an illness process that cannot be approached by a non-sufferer. Most TB participants had clear ideas of what caused their problem and often based it on the germ theory of disease,

Of course I don't know where I picked up the bug ... I could have got it in Thailand ... or anywhere but I assume it was India because I moved around in some slummy areas and travelled on second class trains.

According to some, the bug existed outside and was taken into the body from certain environments, but for others it was present all the time, waiting for conditions (for example: compromised reserve, resistance or immune system) that allowed it to activate. Old age is cited by biomedical explanations as a reason for a depressed immune system however elderly people often have other contributing health issues. In the following descriptions TB also lurks *inside* the castle(body).

I got very weak with this other thing (a bleeding stomach ulcer) ...and according to the nurses, everyone's got TB in them, it's just if they weaken. (Rose 75 years)

Certain drugs, notably steroids or chemotherapy for cancer increase the predisposition to tuberculosis and other infections.

The steroid injection that I had... apparently would have given the TB everything it needed to thrive. (Debbie 60 years)

As previously mentioned, after diagnosis and hospital admission, education about the biomedical model of tuberculosis begins. Dale constructed a terrifying science fiction explanation of the power of TB microbes to spread that illustrate his 'near death' experience and feelings of the vulnerability of his body.

It's like the alien, you know the little bug, big teeth and...then every 24 hours they double and so if you've got 24,000 today, tomorrow you've got 48000 and then it just multiplies at a rapid rate until you're in the million. Well it killed people years ago, it nearly killed me.

In this case, Dale's extraordinary graphic model of the life cycle of the tubercule bacillus may well have had strong implications for his treatment adherence in the face of a difficult 12 month treatment:

It's sort of one of those smart bugs, you know what I mean; it just comes out and pops. Look what it hides in, it's bloody nearly like a bloody steel casing, harder than a walnut shell, you know it just sits there waiting. And as you're killing it off it'll hide one in your body somewhere to make sure that it survives to come back and get you another day. So that's why you have to take, well they explained it to me, that's why you have to take these [pills] so it slowly works, it works on that casing until it breaks through and, "got ya..."

The inhalation of dust or chemicals in their workplace was blamed as a cause of TB by some participants and community members, as was smoking. Danny links the work he did handling asbestos with his first bout of TB. There is a strong association of TB disease with dust and occupational hazards (e.g. coalmining, ploughing, and working in the seed

factory) in the popular discourse of older Pakeha. It is likely that the conception of dust as a source of disease springs also from the health education crusades of the early twentieth century that emphasised good housekeeping as a deterrent for TB. Dick related many possible causes of his TB illness; butchering infected animals during his early working life, inhaling ammonia when he worked at the biscuit factory, or turpentine and dust breathed during his work as a painter. Or,

it could be something I picked up...like you know when you run out of smokes...getting a bit you know sort of desperate nerves...smoke papers...you pick it up and re roll it...silly things like that ...would trigger something like ...could be drinking out of someone else's bottle or something.

Dick's explanation cites multiple possibilities, none of which he is sure about. It is clear that he blames himself for his behaviour. Other aspects of his interview showed the marginal nature of his social existence and self-esteem that contributed to a fatalistic attitude to his health that he felt was beyond his control.

The Process of Diagnosis

The onset of pulmonary tuberculosis is often initially unremarkable, generally mimicking other winter ills such as flu or posing as an unrelenting smoker's cough. Five of the nine TB participants are smokers; all have given up for short periods during their illness, and are further encouraged to during treatment in the community.

Once tuberculosis is suspected, the culture of the TB bacillus can take 8-12 weeks. This liminal phase often leaves the sufferer wondering and worrying about possible results.

Self-Diagnosis, Jumping to Conclusions ... "It May be Cancer"

For David (47yrs), the sudden development of a cough (one year before diagnosis) became a concern which he initially put down to a smoker's cough. His GP did test for TB and upon negative results he prescribed David with antibiotics since he was to be travelling in the European winter. The weakness he felt progressed until he felt "more and more tired and just sort of stiffer and creakier". Although he gave up smoking however the cough stayed with him and when he began to cough up blood he worried that the cigarettes had caused throat cancer. A laboratory test of his sputum showed that he was highly infectious with tuberculosis.

Dale was sick for 2 years, and his doctor put it down to the "change of life". In hindsight, his narrative communicates the fear and frustration at the protracted diagnosis

and at the same time highlights the symptoms (night sweats, fever) commonly experienced with TB:

... hot flushes! I said “listen mate, I’m not ... if this is what women have to put up with, I feel sorry for the b---, because I feel like I am going to burst in to flames any minute and I’m sweating, I can’t afford to lose any more weight.” ... You just wake up and your pillow will be soaking wet. I went on like this for two years, you know, doctors, hot flushes, male menopause, oh, and I said “listen” I said “there’s something wrong” I said, “you know what I mean, you can’t feel like you’re going to burst into flames, self-ignite”.

Despite his advanced state of pulmonary TB, a cough was not the main feature of Dale’s illness.

I didn’t, you know, I mean, I coughed a bit but I thought it was the pot and the cigarettes...

Weight loss can also be a factor contributing to the confusion of tuberculosis with cancer in the early stages. Having just nursed his father with cancer, his assumption that he too may have cancer was initially shared by two doctors.

I thought, “this is it, I’m gone”, and I must have been about seven stone then ... so I actually sold up and came down here to be near the hospital ... I thought, “well I’m gone too...”

A Diagnosis at Last

The infectious nature of his final diagnosis prompted his doctor to knock at the door:

I was sitting there at home, hunched over like this, and ah there was a little shadow, because he’s only about this big, like a little jockey, and he said: “You in there?” I says “come in”, he says, “no, I’m not coming in there.” I says “what’s wrong?”

“I’ve got some good news for you and some bad news. I said well how many weeks have I got?” and blah blah, he said, “no, no the good news is you’ve got TB and the bad news is, you’ve got to come with me now.”

For Dennis the lead up to diagnosis was prolonged. He talked of the frustration of hospital admissions that required multiple interviews with different doctors each of whom asked for an account of his illness story. Finally the psychologist bore the brunt of his exasperation:

...I told the shrink to go to hell! I said psychology is common sense and it doesn’t look like you’ve got much of it!

They went through me with a fine tooth comb.

While the medics were working on a diagnosis, so was Dennis. After a blood transfusion he suggested:

“What have I got, leukaemia?” The reply was: “no, we can’t say at this stage.”

Non-pulmonary tuberculosis is generally non-infectious but can be particularly difficult to diagnose, as was the case for Debbie who had TB in the bone, Frank who had TB in the pleural cavity, and Dennis who had renal tuberculosis. Cancer is a disease that often springs to mind when a cause cannot be found.

Dennis, David and Dale had the experience of anticipating that they had cancer. The final diagnosis of tuberculosis came as a relief that they had a readily curable problem and put an end to the uncertainty they experienced. Susan Sontag’s (1977) well known work about metaphor and tuberculosis exemplifies the contemporary displacement of fear and dread associated with cancer that was once true of TB:

The fantasies inspired by TB in the last century, by cancer now, are responses to a disease thought to be intractable and capricious-that is, a disease not understood- in an era in which medicine’s central premise is that all diseases can be cured (Sontag 1977:5).

Diane’s turmoil was similar but her reaction was the reverse during initial investigations. Her mothering role and feelings of responsibility toward her sick daughter affected her attitude toward her “choice” of disease as she awaited laboratory results. For Diana, the thought of cancer was preferable, she argued:

I’ve got a daughter that’s critically ill...I’ve been living with her for three months and if I’ve given her TB I’ll never forgive myself, I want it to be cancer because I can’t give it to her...her immune system is shocking.

In the early stages, like Dale, she changed her living arrangements to accommodate her feared illness state prior to the final diagnosis. Diana made a rash decision and boarded a plane in North America bound for New Zealand, only later finding out that she had been minimally infectious because she had not been coughing.

“My Friends Knew I had Something”

The social network of people in the boarding house were concerned for their own and Bob’s safety due to his noisy cough. Their belief that “ he [didn’t] look after himself properly” prompted them to demand that the landlord “do something” about his health.

Similarly, Frank was suspected by his social network of having contracted HIV when his health deteriorated:

It never even occurred to me that it may be HIV but a few of my friends were saying to me “well all the indications are there Frank, you’ve had some night sweats, you’re losing weight, you’re not well, there is something wrong, you know, do you need a test?”

...If someone sees you are at home sick and you can’t work and obviously there is something wrong, the question therefore is “what is it?” and people say “oh well he is gay, therefore its HIV.”

Therefore getting called back to hospital clinic to hear the diagnosis “was daunting, I had insisted on going by myself”. Despite the nature of this stressful consultation and his strong social, network Frank sought privacy at the time of hearing the diagnosis possibly to ensure his control and management of disclosure of his disease. The emotional reaction to the actual final diagnosis therefore in these situations can be one of relief at having a treatable disease.

Being Told that you have Tuberculosis

Prior knowledge and attitudes to tuberculosis have an influence on the reaction of the sufferer and their network to the diagnosis of tuberculosis disease. In general, in this study people had little knowledge of TB or thought it was a disease of the past. Recent parliamentary debate has however drawn attention to the higher rates of tuberculosis in migrants from high incidence countries of the world of which some people were aware of.

The reaction of friends and family to David’s diagnosis was one of shock and surprise:

I guess I was more embarrassed, you know I work in an office situation with other people ...apparently I was extremely contagious and of course infected other people, friends...

Debbie’s reaction to the unexpected news was:

“I just couldn’t stop crying, I said ‘this is impossible’...I think he (the doctor) thought I was quite mad, he said ‘you will be cured, it is not incurable’ ...and I mean the usual, why me? Why not somebody else?”

The embarrassment of returning to the waiting room and being unable to control her emotions was accompanied by feelings of shame that her work practices in the health sector would be viewed as faulty and she would be blamed.

“Oh I did feel very embarrassed because I thought that everyone would be saying, ‘oh you know, I think she’s been a bit slack’, you know...”
After two years this remains a difficulty for Debbie.

One of the main concerns for Frank, on finding that he had TB was to allay the guilt his elderly mother felt at deciding not to vaccinate him as a child.

Maybe if I’d let you have the inoculation you wouldn’t have TB now.
“Understandably so Mum, don’t worry about it. It wasn’t your fault, what you did was in good faith” and...the doctors say it may not have prevented this anyhow.

In conclusion, naming ‘it’ generally brought a sense of relief and validation but was also accompanied by shame, embarrassment or shock for the sufferer and their family. These reactions were mediated by pre-existing conceptions of health and prior knowledge of tuberculosis. Once the search for a name for their illness ended, sufferers embarked on a new quest to explain how they picked up the bug that often involved an evaluation of their everyday life experiences prior to their illness. Although treatment plans were obviously outlined by the physician at diagnosis, the realities of this treatment were yet to unfold and be confronted.

CHAPTER FIVE

GETTING TREATMENT

“[They] start to give you treatment, the pills ... [after] about three weeks I started to eat again and I started to feel like I was going to live”

The beginning of the therapeutic phase of the experience of TB illness is often accompanied by a struggle to accept the burden of having a disease that requires extensive treatment for up to a year with accompanying restrictions. The diagnosis of a major disease also impacts on one's identity as a (formerly) healthy person. Participants entered this phase assured of a cure if they took all their medication but, for the large part, were unaware that their biomedical management centred on promoting compliance (or adherence) for treatment completion. Patient education, Directly Observed Treatment and evaluation that is concerned with technologies of bacterial measurement and mediation of the body (X-ray), are the tools of biomedical management of TB. Care during this long term sickness was carefully considered. The end of the long drug treatment highlighted the differing expectations of treatment for clinicians and sufferers.

Going to Hospital

Most participants who were diagnosed with active TB disease were hospitalised as soon as possible after laboratory confirmation to minimise the spread of infection to others. The urgency is illustrated by the recollections of David and Dale, who were visited by their general practitioners to explain the disease and hasten admission to hospital. Both men had experienced a delayed diagnosis (1 and 2 years) that led to the tuberculosis disease being diagnosed at advanced stages and to them being very infectious.

I mean, I went to the doctor in the morning and the result was available I think in the afternoon, and the doctor came around to my house because I didn't have a phone number at the time and said I had to go to hospital straight away. So I just sort of packed my bag and went to hospital. And I was there for 2 months in semi-isolation really.

None of the participants had dependent children and most lived alone, however a rapid hospitalisation entailed an upheaval that brought feelings of resistance and practical concern. For example, after being advised to go to hospital immediately Dale said:

I can't, I said I've got my cat, and I've got to organise the house here,...so I said I'll be up there at 9 o'clock in the morning...

Hospital Life

So once I walked in they grabbed me, put the mask on you and start to give you treatment, the pills. ... [After] about 3 weeks...yeah, I started to eat again and started to feel like I was going to live.

Dale's changing narrative style is interesting here when he moves from a personal rendition to talk of 'you' that suggests a distancing of his identity as a sick person for which the mask and pills are metaphors. Later he reverted to the personal 'I' as he felt better. Earlier in the conversation he had identified with having a good constitution and did not wish to reconnect with the loss of control his 'healthy self' recalled.

After prolonged diagnostic delay, Dale was very ill and although the treatment was quickly effective in giving him relief, to affect a cure treatment was continued for nine months. Once people with TB begin to feel better after initial treatment they can find it difficult to keep taking medication for a prolonged period. Much of the work of the public health nurses who administer treatment is centred on supporting TB patients to see their treatment completed. Biomedical literature about tuberculosis reveals a climate where non-completion of treatment is a major medical concern because of disease relapses and also because under-treatment is believed to contribute to the development of multi-drug resistant strains of TB (Hill *et al.* 2002:185).

People with infectious pulmonary TB are hospitalised in individual negative pressure rooms (vented outside the hospital) to minimise the spread of airborne bacilli. This was explained to me in-depth by participants, all of whom were anxious not to infect others. I asked Rose what the isolation entailed:

Well, *very* heavy doors...they all had to wear masks and so forth and there were two nurses that I just loved" and of visitors, she said, "they had to wear a mask".

Visitors are allowed in their room providing that both the visitor and the TB patient wear masks. Medical and nursing staff follow the same procedures when interacting with patients who need not wear a mask while alone in their bedroom. Due to the long stay (by today's standards) some recreation facilities are provided (e.g. a pool table) and people

considered infectious must wear a mask when outside their room. All hospitalised participants handled this process, although on my short visit I found masks claustrophobic. They were asked to keep out of the hospital canteen but sometimes walked in the nearby park free of a mask.

Despite the available activities, incarceration in the hospital for up to two months, adjusting to having tuberculosis disease and the prolonged treatment required, frequently brought about an ebb in morale and this was expressed by some sufferers when discussing their treatment. They generally felt that there was a high degree of support and care from the nursing staff.

The senior nurse there was *absolutely* wonderful. She's a darling ...she'd come along and sit down and have a chat to me. I recall going outside and sitting with her in the sun having a chat... and she gave me some very positive thoughts and encouragement.

The uncertainty of the hospitalisation period *drives people up the wall*. After initially being told two weeks, the prolonged stay and uncertainty was harrowing for Dale and the intensity of the experience was emphasised by his recurrent raising of the issue (four times) in the course of the interview.

See, they don't tell you, so you were there maybe a fortnight, and you think, I'm going home soon, then you hear someone else talking, I've been here for what's-a-name, and then you start, no one really tells you any thing. It's like a guessing game...and then one bloke he wanted to commit suicide...*not being told*, he said "When am I going home?" And they said, "Well you've got to get your count down," ... it's quite strange, I don't know whether they know and it's a *test*

The expression, 'they,' used to depict the medical professionals conveyed by Dale communicates a feeling of lack of control due in part to the nature of his illness, the power differential that is inherent in biomedical patient consultation, and Dale's misdiagnosis by his first GP (as male menopause). This engendered a lack of trust as he bore the consequences of the delay and felt his welfare was not taken seriously:

These young blokes [doctors]... they've got no compassion ... it's how some of them make you feel.

His lack of trust in 'their' genuine concern for the individual and sharing of information meant that he had to be on guard, lest the lack of concrete timeframes leading to uncertainty be part of a mental *test*. Dale's explanatory model of TB (portrayed earlier) was biomedically based, complete with science fiction metaphors. However in practice,

the nature of his experience of medical interaction combined with the unpredictable response of individuals to tuberculosis drug treatment meant that his fate depended on technological measures. A rational medical understanding was no resolution to his emotional desire to go home.

Dale's suspicion of the medical system was matched by a reciprocal medical distrust of his reliability and commitment to continuing his treatment noted in his medical records. This was inspired in part by his wanderings outside the ward that led staff to believe that he had absconded to go out drinking. One staff member threatened to enforce his compliance by taking his clothes away. It emerged in his life history that he had previously nursed his father with a terminal illness at home. That involved a choice to 'go it alone' outside the medical system. He therefore had previous experience of managing the medical system. Dale challenged the system at every opportunity despite staunchly seeing his hospitalisation through until his "count was down" (three months) and taking his pills for the prescribed time (nine months). At times he took things 'into his own hands' and iatrogenic effects caused him to discontinue one treatment strategy that involved daily inhalations because it gave him

The soft shoe shuffles, I started dragging my feet you know...it wasn't doing me any good at all ... so I stopped it, but they didn't like it you know, me stopping it. And then I felt better again so I thought, well see, maybe it doesn't work for everybody.

His actions (stopping the treatment) were validated by his experience, but meant he was not a docile patient. As he himself said, "I've always been a rule-breaker" and from the staff point of view he was no doubt, 'a handful'. However his lack of conformity also led him to recognise and confront the power inequities inherent in taken-for-granted professional practices when they caused him mental and/or physical discomfort. When ward rounds occurred

They turned the radio off if it was going... they'd all just stand there and look at you...it became a game of silence as to who was going to talk first...I used to say ... "what do you want me to do, dance or what"?

The theme of uncertainty and stress was also reiterated by Dennis when recalling his first experience of TB in the Whareora Sanatorium.

The point is nobody told you how you were doing. I was inquisitive and was told, "let us worry about your TB, Dennis".

The emphasis on Cartesian duality was strong in medicine of this period (1950s), and it was suggested here in a paternalistic way that Dennis should set himself apart mentally from the ‘worry’ of his illness. Of course this was impossible, as an emotional being he was very sensitive to the suffering of others in his company in the sanatorium. “Maori patients didn’t know about TB, no one educated them. Because they didn’t worry, they had a better success rate than Pakehas. Maoris never seemed to worry.” It is indistinct here whether education about TB makes people worry or whether Maori are considered ‘happy go lucky’, as is commonly asserted by Pakeha. Dennis firmly believes that worry affects a healthy recovery. Two people committed suicide and “there were married guys sobbing at night. Some got Dear John letters as their wives or girlfriends left them”.

Of the sanatorium, he said, “It was just like being in the army!” He had an interview with the superintendent every six months, otherwise it was a weekly parade, “line up on the veranda and give the doctor your chart showing your pulse and temperature. People rarely got visitors some people were from Kaitaia, Greenlane, all over”. Modern management of treatment is less overt, but a total handing over of power (required in a sanatorium) in order to be healed is conveyed by Foucault when he says:

But the body is also directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs. This political investment of the body is bound up in accordance with reciprocal power relations

(Foucault 1977:25)

An early discharge was affected by two participants in this study who were stressed by continued hospitalisation. They lived alone, and were at a low level of infection and complied by staying at home and wearing masks in the presence of visitors until their count was down two weeks later. There was therefore some accommodation of personal circumstances when staff was assured that the risk to others was low.

Adjustment to the Medication

For Frank the prospect of nine months of medication and the associated limitations was accompanied by feelings of depression. He was able to articulate how he coped in terms of “lessons” in accordance with his moral, religious, emotional and vocational sensibilities.

...it was only lying on my back in the hospital that the whole thing hit me when they sat down and spoke to me about... nine months of medication. You can’t do this and you can’t have a drink and you can’t do that. I suddenly realised what really it involved in terms of adjustment. And I felt quite depressed. All the things I couldn’t do, but I had hope because I

knew if I did what I was told, took my medicine, I would be better.....I knew I had hope and I was going to get better, and it was a source of strength that at least I could say it's going to be an awful nine months or twelve months but, I am going to be better.

Acceptance is a process recognised by the hospital staff as being crucial to the success of self-administration of treatment. This was elaborated by a staff member as “actual ownership, if you get people to own it then you are half-way there”. Staff will evaluate this during the hospital stay and their judgement contributes to the decision-making process between hospital and public health staff about the preferred ongoing method of drug treatment upon discharge (i.e. self-administration or DOT). The place of treatment is decided in conjunction with the person undergoing treatment, with sensitivity for their needs for privacy e.g. home, work or clinic.

On reflection, Frank (who self-medicated) realised that the time in hospital was

to see that I was a good boy and that I would discipline myself to take my medicine. That's another social issue where people don't take their medicine, we know all about that...so once they decided I was disciplined they let me go home.

There is a moral victory for Frank in being considered adherent or compliant with his medication regimen.

Patient Education

During my fieldwork in the ward, I learned that nursing staff viewed the period in the institution as an opportunity to educate tuberculosis sufferers about the biomedical understanding of the disease and the prospective treatment process, with a view of promoting treatment adherence. The results of this process were evident in the explanatory models of participants as illustrated in the last Chapter. Nurses spoke about the need to go over this more than once and to gain an understanding of the patient's lifestyle through time spent talking on a one to one basis. Pakeha are advantaged, in that the opportunity for repeated conversations is often unavailable to non-English speakers when an interpreter has to be arranged for each dialogue to take place. Each person undergoing treatment is given a tablet chart to keep, showing the medication they will be receiving, with a set of tablets stuck to it so that they may recognise and discuss their medication as changes are made (see Figure 1). The example shown is for a person on daily medication in hospital or on daily self-medication at home. If receiving DOT twice weekly each treatment is likely to include about 20 tablets that are prescribed according to the laboratory results of

sensitivities of the bacilli and the stage of treatment. Although this scheme was initiated to assist non-English speakers, it was offered to all. Judging by the way medication cards were later displayed by participants in their homes during interviews, it was valued by participants because it provided an informative reference and gave a sense of involvement and control in the disease management.

Discharge from the hospital is generally made when the TB sufferer has begun treatment and is no longer infectious. The process of 'getting the count down' is checked through laboratory testing. People whose sputum initially shows TB bacillus under the microscope (smear positive) are generally more infectious than cases that are only culture positive (results may take about one month) (Crofton *et al.* 1999:9). It is common for laboratory tests to show conversion to low levels of infection after two to three weeks of treatment. Specimens of chest secretions (sputum) are not easy for some people to produce if they do not have a productive cough. They may be induced to cough up a sputum specimen by inhaling a saline mist through a mask or alternatively a bronchoscopy may be performed to recover a specimen using a saline lavage. A bronchoscopy is a more invasive procedure if the former is not successful, involving the introduction of an instrument (bronchoscope) into the bronchus of the lungs under anaesthesia to collect chest secretions for testing. Some participants experienced these procedures and spoke about them in a matter of fact way, giving the impression that they had not caused undue suffering.

Community Care of Tuberculosis

Getting discharged from hospital was looked forward to as a therapeutic step on the path to recovery. Reconnecting with social networks also meant in some cases, facing 'contacts' who had been traced and resisted or laid blame on the TB sufferer for their subsequent follow up and threatened infection. One participant said "...they came round again, but a couple of them weren't happy about being tested and things like that..."

After leaving hospital, six out of nine participants had their treatment administered by the Directed Observed Treatment regimen. The DOT strategy means that the participant is watched by a health worker as they swallow the medication throughout the course of treatment (generally twice weekly) (Calder 2001:6). In Auckland, public health assistants may give DOT under the supervision of Public Health Nurses. Although participants mentioned having different people come during their usual nurse's leave and days off, they did not differentiate between the two. The decision to use the DOT method

of therapy is a joint decision made by the public health nurse in consultation with medical and nursing staff when discharge from hospital is imminent.

Many participants were visited at home by the public health nurse who brought and administered their medication twice a week at a prearranged time. At times food items such as a loaf of bread are taken by visiting nurses to accompany treatment for those who have difficulty taking the medicine or show signs of an inadequate diet. The system was not restrictive for the people I spoke with due to the flexibility that the public health nurses apply to their work. David said:

I've just been away to [overseas] to do some work, so of course they couldn't do that [DOT], so they just gave me blister packs dated daily and I just had to commit to making sure I took them myself while I was away which I did. But now I am back I am back on the two weekly visits.

This episode within his illness narrative seemed important for David to show a spirit of collaboration that developed from this period. In particular he takes care to explain that he did not betray their mutual trust. Dale said:

Oh they're very good like that, you know they'd come and meet you wherever, you know, to make sure you get them and take them.

With the benefit of a cell phone:

I used to make sure I was there you know...twice I was somewhere else, and I knew the area they were in, I might have been down Abel Rd or something and I'd just say I'm just here at the garage, call in here...I got to know them quite well in the end you know.

The relationship between the public health nurses and the participants in this study was positive. The terms respect and affection would represent the attitudes that I observed from the sufferer's point of view. As the nurses' case load is divided up geographically their association with TB patients on DOT is a long term one (treatment extending for nine months on average). The encouragement and moral support offered by PHNs was necessary and appreciated by those able to look back on their treatment that "seemed to go on for ever" and often included crises of the patient getting "fed up" with treatment and wanting to stop. The PHNs administering DOT do not wear a uniform or drive a marked vehicle and so the treatment process is not advertised in the immediate neighbourhood and is part of the effort made to protect patient privacy. If necessary, other arrangements can be made for treatment to be given if patients do not wish household members to know that

they have non-infectious TB, such as bi-weekly visits by the patient to one of the public health offices.

In an illness experience that can be exacerbated by stigma, the visiting nurses fulfilled the role of the 'wise', an ally as described by (Goffman 1963), in that they possessed knowledge and sensitivity to the TB sufferer's plight although they had never experienced TB themselves. "Wise persons are the marginal men before whom the individual with a fault need feel no shame [however the relationship takes time to establish and] after the normal makes himself available to the stigmatised, he often must wait their validation of him as a courtesy member" (Goffman 1963:41). At times this relationship included other material support, e.g. on one occasion a PHN wrote a letter to have a phone connected to facilitate contact during DOT.

The quantity of pills made it hard for some... "Oh I had a bucket of pills every day. I think I started off with five different medications". Dale said:

I was one of the lucky ones...because I could just put them all in the centre of my hand and go gulp and they were gone, you know. Some people have to sit there and take one at a time; it could take them half an hour. Some people can take pills and some can't.

Out-patient appointments at the hospital clinic continue throughout treatment (often monthly) and for varying times after the end of treatment. When I accompanied participants to clinic we were first required to attend the X-ray department where participants were X-rayed again. This was an efficient process and during the doctor consultation the chest X-ray was, on some occasions, able to be brought up on the computer screen along with blood test results that the participants had had collected in the same week as the clinic appointment. After several visits I was aware of the frustration (by medical staff and fieldworker) at the high rate of technology failure during consultation. This was coupled with, in some cases, the doctors being unfamiliar with the TB patient, his/her notes, or stage of treatment. This frequently resulted in a consultation that centred on a computer screen (working or not), the doctor scanning the notes and asking at the same time how the patient was and whether they had finished treatment. This meant that the image of the body being treated was mediated (as chest X-rays, laboratory results, and electronic charts in some cases) on screen, with reduced eye and/or body contact between the clinician and patient. An exception was one person with chronic chest disease after TB who had his chest listened to with the aid of a stethoscope and saw a doctor he had previously met at the chest clinic. Because they had met before, I sensed that the

participant was able to converse with honesty about his recent preliminary efforts to quit smoking when the doctor made suggestions.

New Zealand anthropologist, Ruth Fitzgerald (2004:5-6) analysed concepts of clinical care operating at a technical level that incorporated “abstract representations” of the possibly absent patient as well as interpersonal caring skills toward the embodied sufferer. Skills in both areas of care are required for clinicians although doctors emphasised that their first priority for care was to be technically competent whereas nurses embedded a “larger holistic view of the patient” throughout their technical work. A recent survey of elderly people’s attitudes to health care in Ireland showed that “helpfulness and the willingness to spend time talking with patients” was important to participants (MacFarlane and Kelleher 2002:1399). However screens have become a hospital emblem of the body processes of the patient that Frank (1992:82) suggests has led to a medical preference for “hyperreal images that are better than the real body”. Screen images have become a medium of medical diagnosis and communication, replacing the Foucauldian notion of the clinical gaze upon the original body. Similarly, touch has been superceded by images of the “true patient”, so that “the physician’s rounds take place less for him to see the patient, than for the both patient and physician to assure themselves the other is still there” (Frank 1992:83).

Participants made no voluntary reference to difficulties with these consultations to which they had become inured, except in reference to transport difficulties in getting there. One participant explained the need to wash his hands lest the doctor’s handshake was contaminated by the morning’s patients. A role reversal indeed! Multiple providers make continuity of care difficult when appointments are widely spaced and medical personnel are rotated. However I suggest that to make going to these appointments worthwhile for all concerned, time should be allocated for medical staff to review the status of prospective patients prior to the clinic commencing, as is common practice in mental health consultative situations. The PHNs value continuity of care as essential to the partnership relationship they seek to achieve and appear to act as a bridge in some situations by attending appointments with their patients if there are medical issues to raise, as well as generally overseeing treatment. For example, one PHN brought two of her clients to a clinic and attended the two consultations in the same clinic to ensure her clients managed to raise certain issues with the doctor and to remain abreast of the treatment plan. One of the main issues raised during outpatient visits is the possible presence of side effects which are discussed and checked for with reference to various results.

Side Affects of Medication

You Don't Feel Like Doing Much

At some stages of treatment sufferers are required to take four antibiotics to knock back the disease. Their side effects vary. Patients are taught to watch for signs of liver toxicity and caution is particularly important for those with a high alcohol intake and the elderly. Dale explained:

Of course when you start doing those ones [points to tablet on the card], well you feel sick again, you know what I mean, the whole process starts again basically, because you know, after half an hour after you've taken the pills, you just lie down again...you don't want to do much. Then you got everyone saying, come on better get back to work now, that's the last thing on your mind...[After taking them on] Tuesday, you'll come right about Wednesday afternoon and then ...Friday you're back taking them again... It's hard to explain what feeling sick is like to someone who's not sick, I was basically sick for about 3 years.

After the humiliation of his “throw away” diagnosis of male menopause Dale is keen to validate his suffering and his narrative is an opportunity to elaborate on his experience. Despite the effects, Dale persisted with his treatment for nine months. As I went about my research, I could identify with the challenge that taking medication over a long time presented. To continue with the treatment would require acquiescence or a focus on the long term outcome. It brings to mind a popular saying heard relation to sport and fitness, “no pain, no gain”. This attitude was frequently intimated by paired participants about self-control and working to achieve health. These approaches to health and an understanding of the biomedical necessity for the long treatment complement participants' successful treatment outcomes.

Although I was unable to talk with non-compliant TB sufferers, the illness narratives of those with successful treatment outcomes illuminate some areas of potential difficulty in the treatment for all sufferers. The sick role can provide legitimation for the sufferer and care that rests solely on out-patient drug treatment but does not grant the degree of legitimation that longer hospital stays formerly did. As I discuss in the next section, the role of the PHN is crucial here. From the experience of clients under treatment, nurses gain knowledge that they share with others.

Gout

Gout was a side effect of the drugs for three of the nine participants. Danny's wife explained how:

He got very bad gout and he had to go to hospital, it was through keeping him on this tablet about a month too late [long]. The pain was extreme... You wouldn't credit, nobody knows until they have been through it with somebody, because [he] was just crying.

Her explanation reflects an oversight in medical attention to specialist instructions at his clinic follow-up that meant that the offending drug was continued longer than the suggested completion time.

Dennis was on tablets for eight months, they brought on "gout all over, in the arm, wrist and leg". Despite this he made the point that he continued to keep up his TB self-medication however with the assistance of a doctor in his former hometown he accessed an efficient medical treatment that had been useful in the past. "I used to get them and supply jokers in the pub. I've still got some". In accordance with lay advice prior to diagnosis, this informal healing relationship characterises the way that existing social networks may be used as a conduit of health information between one 'experienced' sufferer and another (Helman 1990:57).

Alcohol and Medication

The TB medication and alcohol do not mix well and this aspect was outlined to the participants by the public health nurses but many found this advice hard to swallow. Some participants missed having a drink so badly they checked it out for themselves.

Dale: She told you not to bother with the drink while you were on the pills....I couldn't drink alcohol, I used to drink....I couldn't even have one glass of alcohol, one glass of beer or anything I'd just feel violently ill and start oohhh ... Just one drink I would be like a minor food poisoning attack, one glass...the sweats, like food poisoning...

Frank: I thought I'd have a little sip on a drink occasionally and I promised I wouldn't have the first one for six weeks but then I would have a little drink and I started feeling sick and I realised, well you can't fight your body.

Frank aptly describes his reluctant acceptance of tuberculosis disease, the associated treatment, along with the contingent lifestyle changes through a process of trial and error. Several participants conducted similar experiments before they gave up alcohol. They had to check for themselves that medical opinion was true for them. "You can't fight your body" was a familiar refrain in Frank's interview and I interpreted this as an overwhelming recognition that the physical and non-physical aspects of his whole person are inextricably linked. He could not employ 'mind over matter' as a strategy.

Mental Clarity

Frank: The medication does affect in the end, does affect how you think. I'm sure it does, there were times when I felt ,I was getting that stressed, I put it down to medication, but it could have been the illness as well....I was coming to conclusions, which because I know myself well enough, which I knew weren't me. And I would just say to myself, stop, relax, it is the medication.

Alison: And you did find it reversed?

Frank: Oh yes, yes that's all it was.

On returning to work part-time while still on medication, Frank noticed that his judgement affected. Side effects could cause difficulties in relationships and impair safety at work or when driving or using heavy machinery. When I spoke with an elderly man in the community (who had recent prophylactic drug treatment for TB because he was formerly treated in a sanatorium) his wife was adamant that he was "a bit cranky, he was very quickly irritable, but that was the only side effect, and he is never [normally] irritable". Individuals experience drugs in a variety of ways.

The Sick Role

For those living alone, being cared for begins and ends in the hospital during what is now a comparatively short time. This contrasts to former prolonged stays in sanatoria, where there was an emphasis on rest and restoration of the sick body. The contemporary reliance on chemotherapy treatment for tuberculosis is associated with a widespread move to short stay treatments for medical and surgical conditions, an emphasis on the avoidance of malingering and on a prompt return to the workforce. In Parson's terms, the 'sick role' in contemporary TB treatment is granted for a time during hospitalisation when the sufferer is exempted from usual responsibilities that may be social or occupational (Parsons and Fox 1958: 235). This produces a liminal status for the TB sufferer, who is expected to actively resume everyday activities (ideally a return to work), and yet be dependent on others (compliant) for their pill administration (DOT), being both well and sick and being neither.

Participants varied in the way they managed this liminality. As a partial legitimisation of the sick role therefore, Public Health Nurses (PHNs) administering DOT provided participants (most of whom were home alone) with a measure of tender loving care and frequent short bursts of friendly attention that they enjoyed throughout a long and often difficult treatment. Even those who self-medicated benefited from the check ups, as Frank recalls,

I think the nurse came once a month just to have a chat and see how I was and give a bit of a pep talk and make sure I was taking my medicine but it was really all of a social visit and a cup of tea quite frankly. She was a lovely lady and I quite enjoyed chatting to her.

The meaningful personal relationship that PHNs offered promoted a commitment to continue with the treatment.

Taking Tablets, Managing Time

PHNs managing therapy for these participants took great personal interest in their wellbeing on many levels, keeping in touch by telephone, facilitating other services and providing clinic transport on occasions. The trust formed and commitment toward making the experience of treatment as positive as possible, helped participants through times when they were “sick of taking DOT”. This extended to finding participants that were transient, cajoling people to continue treatment despite lapses in drinking and drug-taking behaviour. The employment of time narratives about therapy to promote and prolong an investment in treatment by their clients have been described Good *et al.* (Good *et al.* 1994:856) in relation to cancer patients in America. As part of “therapeutic employment” nurses present the treatment regimen as stages toward the end of treatment with congratulatory celebration at half-way and end points in treatment as a way of “plotting time horizons” (Mattingly and Garro 1994:773) for their clients. This “chunking” of time was elaborated when participants spoke of treats at the celebration of treatment stages and midway points in treatment were marked in nurses’ notes. After all, the prolonged treatment required of TB means that the end of the illness and the end of treatment do not always coincide, especially if the sufferer has the good fortune to be free of side effects during drug treatment.

Finally Ending Treatment

The ending is celebrated by sufferer and staff alike. Finishing the long-term treatment was an end point that was momentous, especially when it came sooner than projected. This story of completion illustrates the build up to being finished with the pills.

...about nine months, by the end I was sick of it...I recall once toward the end of treatment actually pouring the orange tablets... on my bed and I lined them up and I counted them and I went to my diary and I diared the numbers backwards like 30 through to one, so that every day was one less day of this damn medication because I was so sick of it that I just couldn't wait...A couple of weeks before it was all over I was ticking off these days, you know 30, 29, 28 days to go, 27, 26. About two weeks

before it was to be all over they said “you can stop”. So I came home “Yahoo” and I got them and I poured them into my sink ...I poured hot water over them and watched them melt and run away.”

Other bodily signs signalled the end of medication; “...how excited I was watching my urine come back to a natural colour!” A party at home marked the end of treatment for a family and the caregivers in the public health documentary that featured a child whose family needed great support to persuade a toddler who vomited the medicine into completing his therapy. **TV1**

Having a Drink Again

The restraint and self-denial surrounding alcohol that is required during treatment brought a feeling of having earned a longed-for drink. As Crawford (1985:81) notes, “a disciplinary regime in the name of health is opposed by a belief in the salubrious qualities of release”. Alcohol was significant to the enjoyment of life for half of the participants. However, after the treatment ended, some participants found that they no longer enjoyed alcohol.

Mavis’ Miracle Drug Makes a Marvellous Christmas

Once the treatment ended Dale continued to feel unwell, although he had expected to feel 100 per cent. His narrative is another example of the shared knowledge of remedies among social networks.

I’m just going to tell you the story...I went back to the Doctor and I said “Listen, I’m over that now,” I said “ I’m not a 100 per cent” I said, “ I should be able to run to Otahuhu and back.” He said “Well don’t forget your age” ...but never mind about that ...and I ended up having a duodenal ulcer...maybe the pills I was taking at the hospital or whatever...Anyway I said [to] a friend of mine, “Mavis, I feel sick , you know...I’m sick of this life...I’m just about to end it. I can’t even have a bloody drink ...I feel sick all the bloody time.” She said, “try these”. So I took two of these, I thought, Jesus Christ I could eat a rhino’s bum! Then I got this huge appetite all of a sudden...I rushed down to (the Doctor) and I said “a friend of mine gave me a few of these...”...They done three things for me, they gave me an appetite eh? I wanted to start eating again, I could have a drink and not feel like I was going to die and I had a marvellous Christmas!...that was like a miracle drug to me.

This comic narrative communicates the satisfaction felt at having found his own way around the problem and was in fact constructed in a style that built up suspense for the listener. It ended with a satisfying resolution in that the GP obliged by prescribing the

“miracle drug” (Zantac). As well as a solution to his illness aggravations and reduced lifestyle choices, his personal agency was restored *and* he had a marvellous Christmas!

I Had To Give Up Drinking

When the drugs were finished and he was feeling better, Dennis (75yrs) went up to the club for a couple of beers.

Well I think I had 2 to 3 handles. Well strike me dead, you'd think I'd been on the booze for 3 months- CROOK, never felt like it, ever! I just had to give up drinking. I used to drink 4-5 jugs before I got a spark up. After 2 weeks off the drugs went up to the club but it was like when I was on the drugs...Afterwards I can't eat.

After being 31 stone all my life...now 10 and a half stone. I've lost strength; I used to be a very strong person, now I couldn't lift a sailor off my sheila! If I drink I don't have an appetite as well. I've got to take into account I'm not working...

Dennis' elaboration of the place of alcohol and work in his life gives some background to his feelings of loss after retirement:

I never had any hobbies, I just worked. If I wasn't working I'd drink - you can relax and unwind. I never drank with the people I worked with. I could work 10-12 hours a day and then I'd be tired. A few jugs of beer and I could forget all about the business.

Dennis (a plumber by trade) has a functional or utilitarian conception of health as he relates it to the discipline of the Protestant work ethic he has followed all his life. Work was interspersed with the release and pleasure that he gained from alcohol, because he had *earned it*. His identity is constituted through being a hard worker. These notions of health as control and release in association with work were found by Crawford (1985:82) to be most common in “blue collar workers” The philosophical comments Dennis makes above about the place of alcohol in his life reflect the findings of Phillips (1996:268) who asserts that beer drinking is a key identity symbol of Kiwi masculinity.

Life After TB

A Different Person

The climax of the narrative of therapy completion was associated with a morality of having followed instructions and done the right thing throughout the treatment. “Religious redemption through suffering” is also evident in this narrative that highlights “self-discovery and renewal” (Bury 2001:277). For Frank, with the benefit of hindsight (he had

TB 6 years ago), TB provided a series of teachings, of lessons in life that have contributed to his betterment as a person and in a religious sense. His “trials” had been “a blessing in disguise” (Goffman 1963:21). In part because of his usual influential occupation, he also withstood uncertainty and an uncharacteristic loss of power and control when feeling unwell and through the biomedical control of the treatment process.

Frank: When I became ill, some people said to me, “You are going to come out of this a different person”. I thought what on earth are they talking about? And I think you are because you’ve something more than a cold, you have had a serious illness, not life threatening, could have been, would have been 60 years ago, so I don’t want to exaggerate...

Alison: But it was rock bottom for you?

Frank: Yes and I had to cope with that, for several months, not a couple of days, it was major, it alters your whole life, but I think it taught me a lot about patience and acceptance. I just had to go along and do as I was told which something I’m not used to! (laughter)...I think it taught me a lot about patience and acceptance, there are some things you can’t do, *accept it* because you can’t do anything else, it did teach me some lessons there about myself and attitudes to life which I think plays into other things, you start to work out what you can do and can’t do.

Here Frank contemplates time spent under treatment, in which he experienced a serious illness resulting in an awareness of his positively changed identity. TB has changed his outlook on life. To a degree these changes were predicted by his social network, which was attuned to his suffering and were continually acknowledged by Frank as an asset to his recovery and a feature of his good fortune and “I realised how lucky I am”. Almost as a thanksgiving offering for his safe recovery and renewal, he became an active member of the Tuberculosis Association which accorded with his “values to give something back because [he] has been lucky enough”. He was able to offer his professional skills to the Association and continues to take part in decision-making about the optimum ways of spending funds to alleviate the social suffering of others who have to contend with poverty and TB. As a “representative of a stigmatised category” who is “a little better connected than his fellow sufferers” (Goffman 1963:38), Frank has been able to revive a role (that is rare today) that former TB sufferers historically carried out in the TB Association. Despite being a charity the Association today consists mainly of those with a professional association with tuberculosis. Even though this narrative ended on a high point, not all participants had a positive experience of their changed identity, and some felt a sense of loss.

Biographical Disruption

The upheaval experienced due to illness has been termed biographical disruption by Bury (1982:169) and occurs when “the experiences of everyday life and the forms of knowledge that underpin them are disrupted”. Relations between members of social networks are altered when a member is ill and requires care and assistance with their everyday life or relief from their usual roles. Life plans change and the illness experience brings a renewed awareness of the body in relation to disease processes. Three participants were unable to return to their former occupations, and overall, the completeness of their recovery depended in part on age and pre-existing conditions and status. For many elderly TB sufferers, other health issues also impinge on their wellbeing and influence treatment. Tuberculosis then becomes one of a plethora of issues such as alcoholism, stroke (including speech and mobility problems), gastric ulcer, heart bypass surgery, arthritis and chronic pulmonary disease.

The two participants who were able to “pick up their lives where they left off” (Frank and David) both had forms of sickness insurance that eased their financial situations over with ease and allowed their rehabilitation to occur at a comfortable rate. Frank talked at length about having a supportive workplace and his good fortune in belonging to an insurance scheme that allowed him to convalesce and not be financially compromised. Similarly, David marvelled at an earlier chance decision he made to take up income insurance that meant that he received a generous income when hospitalised for eight weeks. As mentioned before he successfully adapted to working part-time at home. Both men who live alone reflected on how difficult it must be for others to cope when they have dependents and a high chance of losing their job due to prolonged sick leave. The resources available to them no doubt affected their ability to “return to normal”.

The aftermath of Debbie’s treatment has left her “slow and unfocussed, it takes ages to hang the washing out”. She has no appetite. She thought it was due to the drugs, but it has not yet improved. She has lost 10kg in weight and repeats that people say she looks old. She has been away from her job for two years. Debbie has been unable to return to work due to her continued incapacitation by non-pulmonary TB that she acquired in the workplace. This has led to identity challenges for her, that remain unresolved due to the level of incapacity she suffers and the ongoing question relating to the unfairness, “Why me?” Much of her life continues to revolve around the hope of successful surgery to overcome her physical disability and the associated numerous clinic visits in conjunction with accident compensation related appointments.

A residual loss of weight, anorexia and an inability to return to former drinking habits were considered by several to be indication that life is unlikely to return to a pre-tuberculosis state. Weight loss was a significant indication of the initial illness that prompted the seeking of medical advice and after the completion of treatment, weight gain to the pre-TB level often did not occur. 'Normal' body weight and eating well are clearly significant indicators of bodily wellness and figure importantly in a return to a healthy state for this group of TB sufferers. Thinness is associated with illness and a return to wellness is associated with regaining pre-illness bodyweight. In a similar way eating food and consuming alcohol are pleasures connected to feeling well.

Diane returned suddenly from overseas when faced with a serious unknown illness and Dale likewise made a decision to move house "to be near the hospital" due to the ongoing debilitation he felt as his TB disease unfolded. These major relocations were both made even before a formal diagnosis was made. Since treatment, Dale's subsequent work has been intermittent and he commented at length on the hardship of managing part-time seasonal work and the difficulties in negotiating assistance through WINZ. He still carries debt incurred for his rates. "It's an experience, but it's degrading and demoralising". He now manages on an Invalids Benefit.

Rose lives alone in a pensioner flat that had been arranged after initially spending time with her daughter. But as she says "I couldn't get on with her," due in part to Rose's high alcohol intake. She is adjusting to being in her pensioner flat near her sister's home among other aged people with whom she doesn't always get on. She seems lonely but enjoys visits from her sister nearby and recently began to receive home help with showering and household tasks from a person she likes very much. Rose continues "to enjoy a drink" that she initially suggests is for medicinal purposes "to help [her] sleep". She sounds depressed, and said of her severe illness when in hospital: "initially I had lots of visitors, because they got the message that I was dying, you know ...but I don't know why they brought me back. Perhaps it's to help you." Her isolation, whatever the cause, means that she enjoys company when people call.

The biographical disruption experienced by Dick has worsened his already marginalised social relationships (discussed in Chapter Six) and economically, his chronic chest condition means that he is physically unfit to work. Walking to the shops for groceries is an activity he accomplishes with difficulty. Dick has such advanced chronic lung disease at the age of 50 years that at each clinic visit medical staff talk with him about the importance of stopping smoking. He has recently begun a nicotine replacement to

assist him and was committed to cutting down but he declined to visit a hospital clinic for smoking cessation support. Transport is an issue for Dick as he must catch two buses and walking to the bus stop can be difficult on days when he is particularly unwell

For six of the nine participants disruption to their lives caused by their illness has been considerable. Although all are now cured of tuberculosis, life has changed with considerable effects also for their near relations. Frank's illness narrative is exceptional because he depicts the life-changing lessons learned through the experience of tuberculosis as contributing to his "self-discovery and renewal" Bury (2001:276). It could be said that the experience tuberculosis "healed" Frank. As mentioned before, structural constraints have strongly influenced the variable experiences of illness as have the coexistence of other illnesses, due in part to the age of participants.

Hospitalisation constituted a major portion of tuberculosis therapy for three of the nine participants due to the extensive nature of their disease upon diagnosis. Most people were discharged home to continue treatment once laboratory tests found them to be non-infectious. The TB participants displayed varying degrees of tolerance to the prescribed treatment regimens, however all participants adhered to treatment, many with the assistance of DOT. This was assisted by a positive relationship with public health nurses administering DOT, whose care and concern were valued over the long period of treatment in the absence of an extended sick role, which was prevalent in former modes of TB treatment. In contrast, the medical consultations that I observed mediated the body on screen with minimal recourse to the 'original' whole person who had gone to the effort of a visit to the clinic. The computerisation of patient charts and investigations were not running smoothly when I visited and were frequently counterproductive to doctor-patient interaction and to the presumed goals of saving time and paper.

Side effects of TB medication were stoically withstood by most for the duration of treatment, sometimes with the aid of shared knowledge networks, but all celebrated "finally ending the pills". The aftermath of tuberculosis brought varying degrees of feeling healed, despite the medical promise of cure that centred on positive investigative results. As noted previously in this Chapter, the goals of treatment for the sufferer and clinician are at variance despite a medicalisation of community perceptions of health and illness. I return to discuss these aspects further in Chapter Seven.

Figure 1 space

Medicine information chart.

CHAPTER SIX

MANAGING STIGMA

“Most people freak about it, they’re still very frightened of it”

Tuberculosis and stigma have historically had a strong association (Miller 2001). Most participants managed their stigma in the various ways that Goffman (1970) explains and it was initially difficult to identify. One participant, who was already marginalised, exemplified the vulnerability that people who already have minority status have to stigma and he has suffered increased isolation since his TB illness. Because Pakeha tend to view TB as a problem of the ‘diseased other’ (even when they have TB themselves) they find it challenging to accept a having a disease they rarely see in the community. The portrayal of TB in the media has assisted in maintaining the invisibility of Pakeha TB.

Tuberculosis has been a Stigmatised Disease in New Zealand

I discovered that sufferers rarely encountered stigmatising experiences because they withheld information about their disease from some members of their social networks to avoid any possible negative reactions. Only one person described suffering outright exclusion by others that greatly affected his life choices, and that was half a century ago. An elderly community participant I spoke with was overtly rejected in his application for a job after recovery from TB in New Zealand in the late 1940s due to the stigma the disease held for his prospective employers. He found that he quickly got a job when he withheld information about his previous two year’s stay in a sanatorium. In contrast, in the early 2000s, one participant had his staff telephone all the people involved in a prospective project he was organising to explain the postponement of the project for one year due to his TB disease. He was obviously not afraid to publicly disclose his potentially stigmatising illness. It is clear that these Pakeha men experienced their TB illness in two different social

climates. In order to understand stigma in the present context it is relevant to explore the historical development of these attitudes in New Zealand society.

New Zealand History of TB and Stigma

The autobiography of former Member Parliament, Sonia Davies, portrays the lived experience of the stigma associated with TB in the 1940s. The fear of contagion was generally prevalent even between family members. She writes:

I knew Dad was terrified that I might transmit the disease despite the fact my tests had been negative for a year. Many people felt that way, and I hated visiting those who were afraid and who I knew would boil the dishes and scrub the chair I sat in with disinfectant after I left (Davies 1993:68).

Difficulties with regard to the notification of TB cases have been connected to the stigma associated with TB disease in the early twentieth century. Doctors were reluctant to notify TB cases when it became compulsory to do so in 1901 due to the fear of escalating prejudice that already affected employment, housing and marriage opportunities for their consumptive¹ patients at the time (Bryder 1991:111).

The discovery of the tubercule bacillus by Koch in 1882 led the way to the theory of contagion that succeeded a belief in the inherited nature of tuberculosis and contributed in a different way to stigma against TB sufferers. Similarly, the proliferation of tuberculosis in conditions of poverty and its disproportionate affect on Maori, contributed to the multifaceted nature of stigma associated with tuberculosis in New Zealand. Statistics available in the 1930s, show that the incidence of TB was ten times greater for Maori than for Pakeha (Bryder 1991:108). Bryder's (1991) research shows that only some people with TB were considered suitable for treatment. Bryder outlines how in addition to the infectious nature of the disease that others feared, some, due to their "filthy objectionable habits or criminal tendencies ... (were) unsuitable for admission to ordinary sanatoria" (Hospital Board Conference 1926, quoted in Bryder 1991:119).

Whether my Participants had Experienced Stigma

In this study, the people I spoke with were generally not forthcoming about incidents of stigma that strongly affected their experience of the illness. A degree of probing was required that may have been made easier had it been possible to interview members of

¹ Consumption is an historical term for Tuberculosis and patients were regularly called 'consumptives'.

participant's social networks. I therefore found it valuable to have studied stigma theory prior to the fieldwork in order to be sensitive to the subtleties of stigma that were discussed by Goffman, such as disclosure and passing. These aspects of stigma are, by their very nature, not shared with others (especially not new acquaintances), in part because they are managed at an unconscious level by a stigmatised person. I noticed that as I worked with the transcripts over the writing period and reread Goffman's work I finally became more acutely aware of the significance of what participants were saying. For example, Debbie spoke about the "hideous bright yellow piece of paper" that her next appointment was sent on; referring to the fact that it would be seen by the local post office staff through the window of the envelope. Although when I questioned whether the infectious diseases clinic was referred to on the outside of the envelope she said it was not, but in the context of the way she managed her appearances, it was threatening. Therefore the micro level nature of Goffman's work gives a detailed outline of how stigma manifests and is managed by the stigmatised person that would not ordinarily be easily identified in talking with participants about stigma.

Isolation Caused by Stigma

The experience of TB was variable in form and intensity among the Pakeha participants. One person in particular, who lived in a communal setting and sounds to have had low self-esteem and confidence prior to the illness, had his isolation exacerbated after the diagnosis. Fellow residents complained to the landlord with concerns for his health because "he did not look after himself" and appeared very unwell. The landlord pressed Dick to seek treatment. I was unable to obtain a formal interview with the manager of the accommodation but short conversations with her confirmed this. The social group thus attributed a "moral deficiency" (Goffman 1963:13) toward Dick due to the onus of personal responsibility and blame they attached to his illness. When the individual is deemed to have an illness through fault of their own, stigma is most likely to ensue. A Western emphasis on individual responsibility for wellness through 'correct' lifestyle choices that avoid risk, plays in to a blaming mentality (Lupton 1994:91). When Dick returned to his boarding house accommodation (of 15 years) after treatment in hospital, other residents had been Mantoux tested for TB infection (as potential contacts of infectious TB). Therefore, keeping his diagnosis hidden from them, or timing his own disclosure to them was not an option. It was evident through Dick's vague references that other residents had made detrimental remarks about his illness and possible infectiousness.

He was a discredited 'other', socially excluded and morally derided by those he lived alongside due to their fear of contagion.

Dick spoke indistinctly with long pauses and was unable to make eye contact during our conversation as we sat on a disused bench-press in the lobby outside his room accompanied by smells that reminded me of public toilets. He was pale and extremely thin. When asked if he had talked with others about his illness he commented:

I didn't say much about it, even now I don't say much about it.

Alison: Did you have some bad reactions from people?

Dick: Now and again they'd give you a dirty look or something like that but don't really worry me anyway.

Dick's denial that the opinion of others affected him was re-iterated after relating each incident of rejection by others; however his actions speak otherwise, in that his resignation, progressive withdrawal and self-isolation are his coping mechanisms in a communal living situation. In part, due to "feeling lazy", but also to avoid others he found he was sleeping during the day and staying up at night to watch television and eat, while others slept. The manager mentioned that other people in the establishment complained that they could not sleep due to his night-time coughing in the living area.

I stay in my room a lot you know, but, you know, now and then I have a look now and again, you know sort of watch a bit of TV when no one's there or something like that. ... If too many come in I disappear a bit and wait till it gets quiet again. ... That's the only way to go about it, you know, sort of keep your distance.

According to Goffman (1970), Dick's alteration in his behaviour is demanded by the 'normals' and he has been compliant with their expectations.

The "good" stigmatised deviant is therefore expected to take special pains to organize his behaviour and his life in such a way as to save others from embarrassment. For "normal" illness, many normal obligations are suspended; only the obligation to seek help is incurred. But in the case of the stigmatised, a complex variety of new obligations is incurred. Whereas in the former instance the burden of adjustment (through permissiveness and support) lies on the "normals" around the

sick person, the burden in the latter lies on the stigmatised person when he is around “normals” Goffman (1970:).

Unequal power relations between “normals” and the stigmatised individual are inherent but not emphasized by Goffman.

Since contracting tuberculosis, Dick’s social isolation has increased dramatically and his coping mechanisms include a mistrust of people’s ‘friendly intentions.’

Dick: That’s the only way to go about it, you know sort of keep your distance ... so you keep your distance and don’t involve yourself, you know ... like when they get friendly, you know, if they know something, well if they get friendly well then you’re asking for trouble, so you just sort of move aside. It’s the only way I can do it, you know, otherwise they might get nasty ... no loss. They can go their different way.

Alison: And the landlady and people were good about it were they?

Dick: Well they *seemed* good

At the heart of Goffman’s work is the interaction of ‘normals’ and the stigmatised person and the anticipation of the reaction of ‘normals’ stimulates those in Dick’s situation to avoid them altogether and this has consequences. “Lacking salutary feed-back of daily social intercourse with others, the self-isolate can become suspicious, depressed, hostile, anxious, and bewildered” (Goffman 1970:24) Insecurity, suspicion and isolation have become an ever growing cycle for Dick, shown in his quote above, because the more he self-isolates, the less confident he is.

As I spent time with Dick it became obvious to me that he had been a ‘loner’ for many years. He immigrated to New Zealand at the age of 17 years, didn’t keep in touch with his family in Australia and did not have a social network in his adopted home. On admission to hospital he submitted the landlady as his next-of-kin. Dick has been socially marginalised for some time and the stigma of the TB illness has caused him to become more so. The tension of the stigmatised relationship between Dick and the residents resulted in changes in behaviour toward him and by him. His life choices are reduced due to this precarious social acceptance and the stigma of his economic position which results in his relationship of subjection to the group. The isolation of Dick from others has continued long since he completed TB treatment, however, it was not possible to ascertain whether he continues to be stigmatised by the group due to a fear of TB contagion, his

continued symptoms of general lung disease or whether the stigma he has suffered has permanently tainted his identity.

Dick's accommodation appeared barely adequate and as a heavy smoker with chronic obstructive lung disease without a job or a social network, he was most vulnerable to the physical and social ravages of TB disease. His ill health has also compounded his low socio-economic situation in so far as he is now unable to work and draws a sickness benefit. This resonates with Marmot's (2001:12) introduction of **Blane's (2001)** argument, where he states that "the causal direction may be two-way: health may determine socio-economic position as well as social circumstances affecting health".

Dick finds it difficult to walk to the local dairy as he becomes breathless and has to rest part way on a nearby fence. When asked about his lack of energy Dick said:

Oh, sometimes it gets sort of a little bit depressing you know ... if you get where you're going you get quite satisfied, a little bit of you know, ah well, I made it.

His morale and his mobility are threatened. The existing hierarchy of power that characterizes Dick's living conditions on the micro level of his living arrangements and the macro level of his social position have amalgamated to promote a stigmatised relationship of exclusion on multiple levels (Sumner 1994:225). Nancy Scheper-Hughes (1992:373) characterizes Dick's position eloquently:

Stigma is undesired difference. It is everything that makes us turn away in fear, disgust, anger, pity or loathing. To stigmatise another individual is the most antisocial of human acts, for it consigns the victim to a living death on the margins of human interaction.

Effect on Family

Even in our society that emphasises the individual, a stigmatising illness in the family can affect the behaviour of all members and their interpersonal relationships. Although Debbie did not emphasise the stigmatising effects of the disease for herself, she was frustrated by her daughter's ongoing anxiety caused by not wanting others in her social circle to know her mother had TB. Debbie's adult daughter lives with her and the relationship has been under constant strain since Debbie's prolonged illness. Debbie talked of the irritation caused between them because she mentioned talking about her illness to near neighbours. Debbie feels that her tuberculosis causes her daughter great shame. In his writings about the stigma of epilepsy in China, Kleinman emphasises the social course of illness that "occupies an interpersonal space" (Kleinman 1995a) and, in the case of epilepsy, brings

moral blame to the whole family. This leads to families concealing their member's illness, often reducing their treatment chances. It is clear that Debbie's illness has had huge social implications for her relationship with her daughter that perhaps has already-existing difficulties.

'Managing' Stigma

The powerlessness of Dick's position was not met in the experiences of other participants. Efforts to normalise having the disease, such as by attributing it to a celebrity, were sometimes the only hint of discomfort expressed by the participants about having tuberculosis. As I learned more about stigma and studied the transcripts, the more subtleties I began to see. For example Danny's wife commented, "Well look at whats-a-name on Radio Pacific, he's a very good announcer and he had it and he was in the South Island and he was in hospital for five years".

The reactions involving stigma were generally based on a fear of contagion and some participants were initially given a 'wide berth' by friends and extended family members. The participants that were experiencing the disease for the second time (TB reactivation) were able to give a 'then' and 'now' perspective on stigma. Diane was experiencing TB for the second time in her life and a pattern of challenging the established protocol of the hospital stay emerged within her narrative, concerning the management of her mother's and her own TB illness.

Diane contracted TB from her mother whom she nursed until she died and remembers the stigma being worse in the past. Her mother was being taken by bus on a long journey after hospital discharge and was denied an overnight bed with her 'in-laws' to break the journey. Her father was very angry and this caused a family rift for a long time. She explained that TB is still very much a stigmatised disease.

They freak, most people freak about it. They still feel very frightened of it and yet it's not the fear you know ... I thought that it's a long time since there's been any serious TB that people would be, they'd think, oh you know, its something that they did in the dark ages, but they're not, they're still very conscious of TB.

During this recent episode of TB it was noticeable that although the 'young ones' knew less about TB they were fearful of their children being in contact with Diane despite her being non-infectious after 2 weeks of medication. It caused discord within her social network, "it was people on the fringe that panicked", the elders who were around when she had it the first time knew that (due to her experience of the disease) Diane would not "do

anything that would endanger anyone ... she knew how to handle it". For her, being careful and behaving in the appropriate clinical manner would ensure that there was no risk to others and therefore no need for others to react in a stigmatising way. There is an inconsistency here however. Prior to confirmation of her diagnosis of TB in this illness episode, as detailed in a previous chapter, Diane got on a plane and flew home from North America potentially exposing others to TB infection. In conversation about her management of the TB illness she does acknowledge this but points to the extenuating circumstances of her sick daughter's vulnerability to infection that she rated higher than the risk she may have posed to other, presumably healthy travellers.

Fear of stigma was a major concern for Debbie shortly after her diagnosis. She held the expectation that she would have to advertise her TB when picking up tablets at a pharmacy and that visiting nurses would come in a crisp starched uniform, but "they wore nice bright clothes".

"... shock horror I had to have a nurse, you know, I couldn't accept that, here at home I mean ... you know, it was amazing, [I thought] I'd be back and forth to the pharmacy and I didn't want people to know, [people] t...that I'd known for years in the pharmacy to know, but um and she took me to all my appointments and I was offered household help and everything ... I thought ..."

Exposure to TB - Citizenship and Public Health

Behind all my participant's accounts relating to stigma is the notion of contagion. As a child, Diane's mother would not allow her children to linger at her bedside, and she had her husband sterilize her dishes and boil her clothes in a copper, "masks weren't suggested then" and Diane's TB infection only became evident after her mother died. Acting on the 'germ theory' model of disease she acquired from her mother, Diane was careful to absolve her mother of wilful neglect as a vector for the transfer of tuberculosis. Her account reflects how individual responsibility for preventing the spread of TB took on a moral meaning as part of the public health campaign against TB in the early 20th century. Remnants of this campaign continue in health related behaviours considered normal today (Tomes 1997:283). The scientific discovery of the tubercle bacillus in 1882 replaced notions of TB as a hereditary disease and resulted in "a great public health crusade to reshape the individual habits and social conditions thought accountable for its ravages" (Tomes 1997:272). One must remember, however, that this new way of thinking about TB was melded into existing discourse and so contagion theory was integrated into existing theories about the genetic and environmental causes of TB (Craddock 2001:339). The

bacterial explanation of tuberculosis causation had the potential to mark an end to the fear and stigma associated with the disease; however, the perpetuation of stigma against TB sufferers was to be influenced by historical political movements.

Understandings of the risk of contagion and a concern with the effect TB may have on the economic and military vigour of the colony led to health education campaigns that began in the early 20th century (Bryder 1991:111). Prohibitions against spitting in public were conceived in this era. TB surveillance began at a population and an individual level, with the modification of behaviours associated with coughing and spitting and hygienic measures toward the management of dirt and dust and the promotion of breathing fresh, clean air. Because early bacteriology identified the bacillus in “house dust, fly droppings, on drinking vessels and skirt hems” (Tomes 1997:276), a feeling that the dangers of TB lurked everywhere supported the frenetic attempts to sanitise homes and to associate TB with a lack of cleanliness that was in turn associated with the poor. It was later discovered that non-aerosol organisms had little infectivity, but the die was cast and a fear of infectivity from eating utensils and dust is still heard today. For example, an elderly paired interview participant explained that to prevent TB you “should have a good diet, healthy environment, keep your house clean and dust free and don’t go wearing damp clothing, that’s what they used to tell us when we were kids”.

Using a feminist Foucauldian framework, Susan Craddock (2001:339) exemplifies the capacity of tuberculosis to “illuminate fissures of class, gender and race relations”. The normative role of medicine dominated the public health project which was simultaneously a “project of citizenship” embracing the middle-class work ethic, home, hygiene and nutrition (Craddock 2001:339). The role of women as gatekeepers of family health and morality became an instrument of governmentality in the reform of the home and individual, a manifestation of bio-power (Foucault 1998:141).

At an individual level some participants with reactivation TB bore testament to the normalization of these lifelong habits that were learned in an earlier era of TB. Certain behaviours took on particular meanings and prohibitions. For example, Diane explained that her mother originally taught her not to kiss people on the mouth:

because if they’ve got bugs they’ll give them to you ... I’ve got a wee grand-daughter at the moment who I have to fight with every time I meet her because she wants to kiss me on the mouth and she grabs my face and she holds it still ... I have been most careful about that, of course since I’ve had TB ... I’ve not *kissed* anybody ... and I hold my breath

when I cuddle them sort of thing ... when I say goodbyes, I do all these things automatically.

Similarly, Dennis explained that while in the sanatorium he was taught never to use a cloth handkerchief and has carried this teaching throughout his life.

As the 'cure' for TB was not discovered until the 1940s, control of TB relied solely on prevention and on the seclusion of sufferers in sanatoria so that contagion beliefs and individual duty to act responsibly became part of the public discourse of TB, in short it led to "moralising the microbe" (Tomes 1997:268). This was borne out in the stigmatising of "careless consumptives" whose morality was in question and who were often depicted as lower-class.

Experience Counts when it comes to Managing Stigma and Healthcare.

Diane's past experience of her mother's TB illness and death when Diane was 15 years old informed her future attitudes to TB. Her mother made the decision to forgo the risky surgery, as it was a new procedure – "the first three patients had died" – on the basis that it was better for her children to have their mother around for the two years that she was predicted to live. Diane nursed her mother at home until she died two years later. In 1962 when Diane was diagnosed with active TB disease at the age of 36, she had just adopted a child.

I was devastated that I may have the baby taken away. I pleaded with the specialist to let me stay home and he said that he would but I couldn't have the baby of course. The baby was taken away from me, ... given to a friend of mine and she looked after him while I was contagious and they gave me ... streptomycin injection ... everyday, 7 days a week for 6 months. I had a very sore butt and anyway, I had cachets to take. ... it took 3 months before I could have my baby back, [but] they didn't take him away [permanently] that was absolutely wonderful!

In 2002 at the age of 73 when Diane had a reactivation of TB, she once again insisted that she go home and be treated (as she had in 1962 and her mother before her)

... look, I live on my own, please can I go home, ... I know I am infectious, but... with a mask, and they said, "oh yes, you've got to shop" and I said I've got somebody that would shop for me, I'm completely independent, please can I go home? I knew that I could come home and pot about the house and I wouldn't worry about her [her daughter sick with cancer overseas]. ... So I came home and I got people to go and get some macaroni and things like that ... if anybody came to the house I masked and they masked as well, they had their mask at the front door and I made them use it too.

Self-Assertion in the Face of Medical Dominance

In this classical example of Foucault's theory of power and knowledge, it is clear that Diane has power, informed by biomedical knowledge that she carried forward from her previous experience of TB. She demonstrates agency in the face of the hospital system and was able to manage the stigma that others applied, in part due to her biomedically informed explanatory model of tuberculosis. Knowing that she would be non-infectious after a short period allowed her to see the fear of others in terms of a misguided threat of contagion alone. Clear laboratory sputum test results after the initial treatment phase and the use of masks at home, gave her confidence that their prolonged concern was groundless. Her fortitude remained, despite being told that she would never get 'it' again after the original treatment. She has a good social network and manages to save airfares, while living on a pension, to visit her sick daughter overseas.

Dale had a very matter of fact way of acknowledging stigma when questioned closely about it; and in hindsight is able to say that he did not allow the reactions of others concern him greatly.

Alison: What was the reaction of the people around you to tuberculosis?

Dale: Oh some of them, once they'd find out ... they'd make a few enquiries about it and then they'd run for cover, you know.

Alison: ... Because they were frightened. ...?

Dale: Well yeah, I don't know what they're frightened of, whatever, you know.

Alison: ... so did you feel a little bit isolated by ...?

Dale: Yeah, didn't worry me that, you know what I mean, they all came round again. ... A couple of them weren't happy about being tested and things like that you know.

Alison: So there was a bit of a reaction?

Dale: A little bit, but not much you know because they were friends of mine, so ... And they're still there so ...

As Dale recovered from TB 5 years ago, the benefit of hindsight and the fact that the friendships 'survived TB' may have assisted him in downplaying the immediate effects stigma had on him. It is evident then that a 'spoiled identity' caused by stigmatised attitudes was not permanent.

It's *They* That Have the Problem.

Similarly, Dennis was adamant that the problem of stigma did not lie with him. He first had TB in 1950 as a 21 year old and spent 2 years in a sanatorium. In referring to the 1950s ...

Stigma? Only the ignorant. At that stage Mantoux showed that 92 per cent had contact with TB germs. The Mantoux testing is not done now so they wouldn't know.

He deduced from this that there were a lot of undiagnosed infected people out there. As he had been recently medically assessed Dennis felt he had an advantage of knowing his TB status when those undiagnosed others were unaware of theirs. The 'correct' biomedical knowledge he accumulated about TB while under treatment gave him the 'upper hand' and he was able to use this against 'ignorant' others. When he came out of hospital, others were standoff in public and he managed the situation by ignoring or teasing them, getting in first, so to speak. In the pub he would tease:

Don't come and drink with me or I'll give you TB. When did you have your last chest X-ray? I had one last week ... Gradually the public are becoming educated. When I was a kid, cancer used to be a dirty word.

He believed stigmatising attitudes to be a fickle phenomenon according to the fashion of the day and (in hindsight) presented his resilience. Recently, during a reactivation of his tuberculosis, Dennis "couldn't pick" any change in attitude when he told people he had TB, although this time his TB was non- pulmonary, and therefore non-infectious.

And for Frank, the problem lay with others:

When you tell someone you've got TB if they have a problem with that well that's their problem, not yours...if you have a problem with that well that's your problem, go away.

The above examples show the active management of TB stigma and an active participation in healthcare. However, these were not found in the internalized stigma that characterized Dick's stigma management. As members of the majority group, most Pakeha TB sufferers I met were able to manage stigma in the midst of a health culture of which they were an active part. Most participants did not suffer multiple minority positions in the society since they were aligned with the dominant culture, thereby having a widely accepted power and knowledge resources upon which they could effectively draw.

Community Attitudes to Tuberculosis

“... you associate it with new immigrants, or asylum seekers or people from third world countries ... everyone was surprised”. (David)

The attitudes of the community to TB are at the heart of (enacted) stigma or discrimination experienced by sufferers. As previously noted, there has been a recent shift in the analysis of stigma toward a view that sees the source or problem of stigma as being in society rather than in the ‘imperfect’ individual. The history of tuberculosis in a region, personal experiences of the disease and local health cultures influence community attitudes to those who suffer from it. In general conversation about my research among Pakeha it quickly became clear that age affected people’s encounter with the disease and those who knew little about it saw it as exotic, from elsewhere. In discussing community attitudes to TB I will present further paired and TB participant feedback about the perceptions of TB and sources of health information and relate them to the work of Crawford about the diseased ‘other’. A brief portrayal of tuberculosis in textual and television media will follow in relationship to current ideologies concerning immigration and TB and how these influence the experiences of TB participants in this study. As part of paired interviews about conceptions of health and illness I asked participants about tuberculosis.

Have you Heard of Tuberculosis?

The nine paired participants ranged in age from 49 to 74 years and all had heard of the disease. I asked them to describe TB and to tell me their ideas about who was likely to get it. Eight of the nine participants associated flu like symptoms with TB, most mentioned coughing specifically. Eight people related the germ theory of disease with the cause of tuberculosis. When asked who is most likely to get TB five people associated tuberculosis with overcrowding and one man blamed “overcrowding caused by overbreeding” within ‘other’ ethnicities (that I shall not name). Poverty, usually in relation to overcrowding was mentioned four times as a cause of TB, also damp conditions, poor hygiene and sanitation, house and coalmining dust, and unpasteurised milk (that participant grew up on a farm). Personal circumstances and stage in the life history seemed to dictate knowledge about tuberculosis illustrated by the fact that paired participants over 60 years talked with the most confidence about the disease. In reply to who is most likely to get TB, migrants from the Pacific and Asia featured strongly.

I asked them to recall how they learned about the disease. Those aged 60 years and over grew up knowing about it because it was in the community. Fleur went to school in Ruatoria where she said “a lot of Maori children had it. I went to hospital with rheumatic fever and I was pretty conscious of the fact that some kids there had TB”. She recalls her brother in law contracting TB aboard ship when he sailed from the UK and shared a cabin with someone who coughed incessantly. One man (73 years) said that it was just part of growing up, “it was a fear disease for a while, but nobody in my group had it”. The disease is feared by this man but because it was or is stigmatised, he wanted to deny any close association with TB. Similarly another man said that “We were terrified when we got a cold that it might be TB! ... We used to have medicals in school, afterwards you got a lecture”. Many had heard of TB through school and some younger participants recall TB vaccinations at high school as their first exposure to the disease. Interestingly one woman (56 years) learned of TB through reading novels that involved sanatoriums in Europe. Overall, living at a time and in a region where TB was more prevalent raised their awareness of TB, and education in schools featured as the predominant modes of learning about TB.

Hence, for half of the participants, tuberculosis is a disease of other ethnic groups and this attitude was reiterated in general discourse about TB by Pakeha I spoke with casually over the course of my research, particularly in regard to immigration. Community attitudes held by the sufferers of TB thus affected their acceptance of a disease, given that they had preconceived ideas of the disease.

A friend (50 years) of mine said that her father had TB “but he got it in the war”, thereby stressing that it originated outside his environment. Similarly, David (a TB sufferer) says he may have caught TB while travelling in India on second-class trains, although there is another possible source of his infection as his grandfather, who was an alcoholic, had TB in the 60s. He recalls the shock of his diagnosis because he and his network related TB to ‘other’ people:

... shock, because it’s sort of not a disease we think of in this country so much, or if you do, you associate it with new immigrants, or asylum seekers or people from third world countries ... everyone was surprised. I guess I was more, embarrassed.

Because many Pakeha do not usually know local people with the disease it is an unexpected shock to be linked to an illness that they associate with the effects of poverty that lies outside their own group identity. When David (as a New Zealand born Pakeha)

spoke to me on another occasion, despite suffering the disease himself for over a year, he still basically expressed the same view of the disease, as a problem of immigration that required government intervention. This is no surprise as Goffman says, “normals who live adjacent to the tribally stigmatised often manage handily to sustain their prejudices” (1970:70). Frank, however did seem to review his thinking due to his experience. In relation to community attitudes he said:

The reaction was almost universally, “I thought people didn’t get tuberculosis these days and if they do, it’s poorer people”. And in my case I live in a nice home, I have all I reasonably need, I certainly don’t live in wet damp conditions, I have good food and so the reaction people have to be reminded [of is] that tuberculosis, like cancer, strikes anywhere without warning and it’s not limited to a particular race or social strata, anyone can get it ... I never at any point sensed a stigma, what I had was surprise.

The dread associated with cancer, as a disease that can strike anyone is conveniently likened to TB so that although he distances himself from conditions of poverty he rationalises that in fact anyone can be vulnerable to TB.

Disclosure

Both of the above men related a bold approach to disclosing that they had TB. According to Goffman (1970:17), those with a strong sense of self-identity “may fail to live up to what we effectively demand of him ... He bears a stigma but does not seem to be impressed or repentant about doing so”. On self-reflection perhaps their boldness took my attention because it is uncommon for someone with a stigmatised disease in my own social group to be so outspoken about it. They managed the threat of stigma by challenging the ‘normals’ (to use Goffman’s term) to confront their tuberculosis. Almost as a form of impression management or “information control” in the reverse of the way Goffman uses it, by being forthright the “discreditable” gain some control over conclusions others may jump to. As a gay person, whose friends thought he might have HIV, Frank added the self-reflection that “I suspect that it was, well; let people know what it is before they conclude it is something else wrongly”. It was better to front up with a malady that is less blameworthy in the eyes of the community. Many of the TB sufferers do not recall being stigmatised, and because they live in a culture that holds preconceptions of TB as a disease of the ‘other’ they carry the same “systems of honour. The stigmatised individual tends to hold the same beliefs about identity that we do; this is a pivotal fact” (Goffman 1970:57).

In using the term 'we' Goffman refers to 'normals' like himself that denotes the mainstream middle-class in America. From the same part of the world, Crawford's thesis argues that boundary maintenance fosters the upkeep of group identity of which health is a crucial component (Crawford 1994:1348).

Another way of viewing the 'other' is as a source of pollution. Drawing on the work of Douglas (1966), Sontag argues that it can be shown that:

There is a link between imagining disease and imagining foreignness. It lies perhaps in the very concept of wrong, which is archaically identical to with the non-us, the alien. A polluting person is always wrong, as Mary Douglas observed. The inverse is also true: a person judged to be wrong is regarded as, at least potentially, a source of pollution (Sontag 1989:48)

As {Herzlich, 1987 #405} discusses, an epidemic of disease is frequently blamed on outsiders. The understanding of the 'germ theory' of illness that conceives TB as caused by a bacillus may foreground a belief in a social cause such as overwork or that it was brought by an outsider (Herzlich 1987:106). Historical accounts often relate that the plague was brought to a region by an outsider; similarly, participant's accounts of tuberculosis spoke of it as being brought to New Zealand by outsiders.

Sources of Health Information

The paired interviews I conducted show that, after their doctors, participants use the media as their foremost source of health information. In comparison, Chambers and MacDonald (1987) study of middle-class Pakeha women cite friends as a primary source of health information. However their study differentiates between newspaper and magazine sources and when their figures are combined, as in this study their results show the printed media to be by far the main source of information. Thus the media plays a strong role in disseminating health information and I argue that they have a responsibility to minimise fear and hype that stigmatises minority groups by presenting health information in a fair manner.

The appearance of TB in the media is not uncommon, and a recent proliferation of articles that falsely associates the disease solely with immigration have appeared. Headlines such as *Health Alert on Asylum Seekers* (Gregory and Mold 2002:11), *Burden of Immigration Health* (Fox 2002:1), *TB scare* (Anonymous 2002b:3), *TB fears over Asian students* (Anonymous 2002a:2), *Door Shut to TB sufferers* (Tunnah 2004:A5) promote a climate of fear and stigma toward TB and minority groups.

These attitudes, reiterated in the media, reinforce the notion that TB always comes from outside and as a contagious disease may escape from the “imagined ghettos and enter the presumed zone of safety, designated ... as the general population” who may become its innocent victims (Crawford 1994:1356). Health has been emphasised in a notion of citizenship in recent discourse about immigration that has been pushed by right wing parties associated with the re-emergence of assimilationist policy. This has set the scene for the next elections to be centred around issues of race and citizenship. The relentless campaigning of New Zealand First MP, Winston Peters has promoted attitudes that associate infectious diseases with immigrants whom he describes solely in deficit terms. Statements in Parliament such as “we are a net importer of diseases” (Peters 2003:11.9.03) shape ideologies of the ‘diseased other’. To this end, the recent release of a “socially inflammatory” New Zealand First pamphlet about immigrants being a source of Third World diseases that cost the taxpayers money, cause public transport congestion, housing difficulties, and welfare and education problems, is divisive (McLauchlan 2003:6.11.03).

Peters misuses the health surveillance documentation gathered about individual bodies who have come to New Zealand from elsewhere as “statistical bodies” (Woodward 2003:225) to furnish his ongoing political career, with complete disregard for the harm (in the form of stigma) this will inevitably bring to these people who are embarking on ‘new’ lives as newcomers to the community. From his position of power their suffering is collateral damage, the outcome will be the stigmatising and social exclusion of immigrants and an overall loss afforded by preventing their full participation in New Zealand communities. The political power and influence of Peters has attached a negative value of difference to minority migrants (who are often easily identifiable) so that all are suspected of carrying communicable diseases that the majority then has an irrational fear of contracting, as witnessed in the recent SARS outbreak. The result of a spoiled identity is often social isolation causing a lack of access to the resources of society that the ‘in’ group enjoys. In short, migrants who are excluded from the community lack social capital, defined as “the norms of reciprocity and trustworthiness that arise from social connections among individuals” (Muntaner and Lynch 2002:261). Moreover, recent evidence shows strong links between diminished social capital and tuberculosis (Holtgrave and Crosby 2004), thereby stressing the need to increase social connections as much as possible (Miller 2001).

A constructive approach to disseminating information about TB appears in the content of an article in *The Dominion* (Betts 2003). It draws on the personal illness story of

a Pakeha lawyer who suffered TB recently and in the process gives clear information on the symptoms and treatment available and effectively defuses panic and misinformation about TB as a disease of the 'other'. The downside of this article is that a large colour picture of an obviously 'Asian' TB sufferer being treated in Hanoi accompanies the text. This has the effect of misconstruing the textual message that TB does occur in Pakeha New Zealanders, especially for those who briefly scan the newspaper. Another illustration of Pakeha in connection to TB is only offered in relation to "Kiwis on trail of TB cure" (Collins 2003), an article about the research efforts to develop a cure for the 'other' with multi-drug resistant TB. These two articles (see Fig. 2) show the role the media can play to "reinforce the power of dominant cultures and beliefs" (Dew and Kirkman 2002:188). There is clearly a dominant discourse of tuberculosis as a disease of the 'other' that is reflected in the media.

A medical soap opera, *Shortland Street* is a long running television programme in New Zealand that incorporates current health issues. I became aware that they had included a storyline on tuberculosis when my teenage son volunteered that he knew about TB although he hadn't met anyone with the disease. I asked:

"What did you find out?" and William said: "that you have to take your pills for the whole time".

On viewing the five episodes covering the TB storyline I was impressed with the portrayal of TB in a fictional Auckland community. Although the story involves multicultural players the original TB patient is depicted as a Pakeha person who returns from overseas and has a reactivation of TB after five years due to non-completion of treatment. As compliance with medication regimens is a perennial concern for public health management of TB it was a valid way to reinforce notions of TB as a serious (the patient dies!), infectious (another debilitated patient 'catches' it) disease, that must be completely treated. The diseased person did arrive from outside New Zealand, implying that it originates from elsewhere but overall the programme effectively disseminated health information as entertainment to a young population that I have observed to have scarce prior knowledge of TB. It was presented in a way that did not augment stigma surrounding tuberculosis.

Conclusion

Stigma is an ongoing problem for sufferers of TB due mainly to an exaggerated fear that they may spread the disease. The heterogenous group of Pakeha included in the study poses varying degrees of resilience to stigma influenced by their social position, historical experience of the disease, social support and explanatory models of tuberculosis. The experience of stigma for Pakeha as the majority group was defined in relation to the 'other' minorities. Community perceptions of TB relate it to the 'diseased other', to migrants and poor people that are generally not part of their social group as the dominant culture. The reduction in the incidence of TB since World War Two has meant that to an extent it disappeared from public view especially for Pakeha who had little contact with TB sufferers. Similarly, as the incidence of TB declined, public health education and TB control activities diminished so that the recent media and political attention to TB in association with immigration is the only source of knowledge for younger people who have not 'met' TB before. The emphasis on the diseased 'other' supports a denial of TB in the dominant group, whose elderly are vulnerable. Tuberculosis disease in Pakeha has disappeared from view for the public who are deluded in believing it has vanished. TB disease is thus largely invisible for Pakeha in New Zealand.

See Fig 2

Figure 2.

CHAPTER SEVEN

DISCUSSION AND CONCLUSION

“People said, ‘this will alter you, you will come out of this a different person’.”

Managing a long period of TB treatment was difficult for all participants and I am reluctant to frame their diverse experiences in generalities that reduce their particular experience of suffering. However, several themes emerged from the experiences of participants in this study. They are; tuberculosis in relation to time; its invisibility; the elderly; healing; and care. *Time* is a recurring theme in the long treatment of TB for Pakeha and because it is an ancient infection I argue that it is often experienced amid preconceptions that situate TB as a disease of the past, no longer thought of as a threat to the dominant group. It is also often conceived of as a recent problem of the ‘diseased other’ (outsiders, migrants) who are blamed and stigmatised for bringing the disease from outside New Zealand. Community attitudes that stigmatise those with TB and negate the disease risk for Pakeha contribute to the *invisibility* of TB for this group. I found that this had consequences for a timely diagnosis and for adjustment to having a disease that is no longer associated with Pakeha. In fact diagnosis is particularly difficult in the *elderly* (over 70 year olds) who are disproportionately affected by TB in the Pakeha grouping. The nature of the TB organism means it can persist in the body after prior exposure to TB infection over a virtual lifetime and develop into TB disease when other factors compromise the immune system. In the elderly, TB is therefore sometimes experienced amid other health problems and feelings after treatment do not always equate to feeling *healed*. As a group, the participants were all compliant and I propose that this relied on their previous experience, their attitudes and the social context of their treatment under the *care* of public health nurses. This has implications with regard to the successful implementation of the international recommendations for DOT because I interpret the social process of delivering DOT to be pivotal to treatment success. This chapter discusses these themes and their implications.

Time and Tuberculosis

TB is a disease of time; it speeds up life, highlights it, spiritualises it. In both English and French, consumption ‘gallops’. (Sontag 1977:14)

Consumption (the old name for TB) eventually consumed the body in an era when effective treatment was unknown and the disease was often terminal, thus shortening the lifespan of many. However, even now when effective treatment is available, but extends over a long period, participants have shown how such a serious illness has highlighted their sense of time as they reflected on periods before and during their illness. The time involved in effectively treating TB brought challenges for participants, for those supporting them professionally and for family members. Although the early weeks of treatment usually brought relief from symptoms, the reality of taking medication for up to a year that often caused side effects and demanded lifestyle adaptations that was hard to bear. Although some participants reported no side effects, the pain caused by gout made the continuing treatment particularly difficult and necessitated more medication to control the pain. I found that several participants were high users of alcohol and abstaining throughout such a long treatment was particularly hard. The time-span for TB therapy is usually designated by the chest specialist at the outset of treatment so that as the time under treatment passes, a sense of anticipation builds toward a climax until medication is complete, as illustrated by my account of Frank lining up his pills on the bed. Time is regulated by PHN visits on pill-taking days and how the effects are managed. Being home and available for medication visits structures each week but in Dale’s case, the time of the week then also affected his well-being. He described earlier (see chapter 5) the fatigue and unwell feelings associated with the day following medication.

PHNs manage time for their clients in various ways. Because they are aware of the strain of the protracted nature of TB therapy they celebrate half-way stages of courses of medication and completion with their clients, in order to encourage a sense of progression to an end point. This has been termed therapeutic emplotment (Mattingly and Garro 1994) and serves to provide a sense of certainty and hope for the sufferer as an aspect of care. As professionals, PHNs also provide surveillance and treatment serves to “reveal a linear time whose moments are integrated, one upon the other, and which is oriented towards a terminal stable point; in short, an ‘evolutive’ time” (Foucault 1977:160). The timely interventions of DOT visits suggest an evolutive time but also moments of progress, each

dose is one less to swallow, as Frank noted when he marked the last days of medicine off in his diary. As PHNs go about their work (involving other infectious diseases as well) their time management is centred around their client visits so that their time is used productively. Time management also involves plotting their routes around the city so as to minimise their travelling time. In this way PHNs are themselves disciplined to maximise their production. “Power is articulated directly onto time; it assures its control and guarantees its use” (Foucault 1977:160). Power flows in many directions affecting different levels, in this case TB sufferers and health workers through the management of time.

“Time associated biological vulnerability” has been discussed by Wadsworth (1997:864) in relation to “the biological and social experience at the earliest times of life”. TB is particularly susceptible to this generational effect. TB infection may stay dormant in the body after exposure during historical periods of high community incidence. Those born 50 years ago have “crossed periods of great change” (Crawford 1994:864) so that the prevalence and awareness of tuberculosis and its treatment has changed from one “historical moment” to another (Blaxter 2000a:37).

As a social disease the living conditions of each period are relevant to the infection and emergence of disease. Accordingly, Blaxter (2000a:28) writes that “the very meaning of class changes with time, and so do the variables which are used to represent the phenomenon of ‘health’”. While half the TB participants are pensioners living on a meagre income their previous occupations create limitations in determining a relevant living standard, particularly for women. Personal experiences of deprivation in childhood require sensitivity to elicit during interviews. However, two participants who first had TB when young, mentioned poor housing conditions during childhood and in another case, inadequate available treatment in association with their original tuberculosis. Childhood exposure to TB during the World War Two period was explicitly mentioned by Diane who actually nursed her sick mother in the terminal stages of the disease and blamed her mother’s TB on their family’s cold and damp living conditions. The incidence of TB at the time was certainly high, affecting exposure to infection.

As I have elaborated elsewhere, the medical treatments for tuberculosis differed considerably from current treatment; antibiotic treatment for tuberculosis was introduced in New Zealand after World War Two and prior to that the mainstay of treatment was rest and diet and segregation in a sanatorium with some surgical lung treatments. The treatment the participants received that was thought to be curative at the time has resulted in reactivation.

Present treatment is not expected to allow reactivation; however, only future research will confirm this.

Attitudes to risk factors have also changed across social time. For example, the health effects of habits such as smoking have altered over the life-course of the aged today. Exposure to (parental) smoke during childhood has now been shown to affect respiratory health and may be implicated in whether a young person succumbed to TB infection or disease in their youth. Recent research in fact shows that smoking is a risk factor for the development of TB disease in infected people (Gajalakshmi *et al.* 2003). Dennis noted that smoking was acceptable when he was moved to Whareora Sanatorium (in 1951):

In those days doctors smoked, [and] patients would ask, “is it alright if I smoke?” and the doctor would say, “so long as you don’t cough on the kids”. In Wanganui [in 1950] you weren’t allowed to smoke, the sanatoriums were all run differently.

For those suffering TB reactivation, the period of life when the infection may have been acquired or the disease treated comes under scrutiny and importance in personal narratives. As Mattingly and Garro (1994:771) say, “through narrative we try to make sense of how things have come to pass and how our actions and the actions of others have helped shape our history; we try to understand who we are becoming by reference to where we have been”. Biographical time may be measured socially according to events, for example, Danny, through the words of his wife, indicated that he first had TB when he was “in the dairy”, an occupational stage in his life. Tuberculosis has a unique connection with time due in part to the tenacity and lifespan of the causative organism that allows it to remain dormant and reappear as disease later in life. When the disease re-emerges, then time becomes structured from without by hospitalisation, medical appointments and treatment regimens. Stages in the lifecourse are framed around TB for some, as “before TB” and “after TB” or everyday life may be focussed toward the future, “when the treatment ends”.

Pakeha TB is Invisible

The historical decline in tuberculosis has led to the belief that for Pakeha, it is a disease of the past because it is not often seen in the context of their everyday lives. This was especially evident among younger people, whereas people who were middle-aged and over knew about it because it was in the community when they were younger. Although living standards for Pakeha are generally higher than for other ethnic groups tuberculosis is still a

problem, particularly for those who *are* poor, the elderly and those with other predisposing conditions. However, I agree with Crawford's (1994) thesis which holds that health is important in the construction of Western's identity, and that this is reflected in concepts of a healthy self and how we view others in relationship to the self. At times of change, such as during periods of increased immigration when identities are threatened, identities are contested and group boundaries are tightened excluding the 'other'. Tuberculosis has been constructed as a problem for the 'diseased other', evident in talk about TB in the community and in the media, resulting in health being one of the grounds on which migrants are marginalised.

When migrants are stigmatised for having TB disease other groups susceptible to TB are hidden. Differences are constructed through defining the abnormal and hence the normal in Foucault's (1977) concept of bio-power. In the process of dividing the healthy from the sick, majority from minorities and spatially separating them, differences are upheld. Since the early twentieth century there has been a recurring pattern in New Zealand of the marginalisation of immigrants because they were viewed as a tuberculosis threat (see Chapter One). So as a member of the dominant group, when a Pakeha person is confirmed as having TB, they are often challenged to confront notions of control and regulation of the body that form part of their perceptions about the 'healthy self'.

The shock of adjusting to a disease that is perceived to belong to another era or to outsiders has been discussed in Chapter Six. I felt surprised to hear from some participants with TB about the problem of TB and immigrants, despite being New Zealand born themselves and probably contracting it in New Zealand. A common statement was; "I don't know why they don't test them before they come in". This same person later said: "...like refugees, like I say, come into the country. They get everything...we New Zealanders, we've got to fight for every dollar". Because having TB has implications for self-identity it follows that comments such as these assist Pakeha sufferers in protecting themselves from feeling symbolically connected to 'infected' others (Crawford 1994:1348). In these situations it becomes clear that outside the confines of hospital it is unlikely that these people would want to join a TB support group, for example, as has been useful overseas with the creation of "TB clubs" (Demissie *et al.* 2003:2009). This also highlights a possible reason why there are virtually no ex-TB patients represented in the Auckland Chest and Tuberculosis Association, the charity set up to assist TB sufferers and their families and formerly run by ex-TB patients.

Delays in diagnosis have been linked by participants to perceptions among doctors that TB among Pakeha is unlikely because it is invisible. As mentioned before, delayed diagnosis of TB for elderly people is sometimes fatal and it is therefore vital that their susceptibility to TB should not be invisible.

Tuberculosis and the Elderly

Those aged 70 years and over have the highest incidence of TB in the Pakeha population and four of nine TB participants were in this group and all suffered reactivation of past disease that was treated differently years ago.

My enquiries to medical personnel about TB disease reactivation suggested that non-compliance or inadequate length of treatments was the probable cause of incomplete cure of TB disease treated in the post-war period. As mentioned earlier, previous experience of TB helped patients to manage the disease a second time, particularly with regard to stigma. I met these people with reactivation TB after treatment completion and was surprised at their acceptance of their plight that necessitated they be supposedly 'cured' twice! These sufferers made me aware of the huge changes in emphasis on treatment for TB over their lifetimes. However, notions of 'cure' need to be seen in context. After their recent treatment completion for TB disease, three of four elderly participants continue to have other health difficulties such as stroke, alcoholism, chronic chest problems and heart disease. In keeping with difficulties in diagnosing TB in aged people there are often multiple problems in adjusting to the drug treatment when there are co-existing health problems, as side effects occur more often in the elderly.

As the proportion of the elderly population rises it is likely that numbers of Pakeha and Maori elderly with TB will rise because they began life during an era of endemic TB (Zodgekar 2002:96). However, there is no general community awareness of TB in the elderly. Paired participants tended to focus on migrants as the only 'at risk' group. This invisibility of tuberculosis in elders will likely create difficulties within those families who consider it a disease of outsiders if an elderly family member is diagnosed with TB.

Cure sans Healing

Dennis: I was a real go go person, worked 7 days, 16 hours; it didn't worry me going all the time, [but] not now.

Dennis refers here to his former reserve of health that has been described as part of many Pakeha's cultures of health. It is depleted when a person is 'run down' or ill and 'builds up' in good times when a state of equilibrium is achieved. During periods of equilibrium the body can withstand abuse or stress in today's terms, allowing a person to keep going for long periods if they have to.

If I could have my appetite back and stick on a bit of weight, I've told the doctor that dozens of times ... I can't sort of enjoy my retirement.

A permanent weight loss means for Dennis that life had not returned to normal, the healing was incomplete in his calculation as he considered it a vital sign of health.

Although Dennis has raised this concern "dozens of times" with doctors it has not been interpreted as constituting a labelled disease or condition that the doctor thinks requires intervention. Although Dennis also experienced cardiac problems he blamed TB for irreparably changing his life and forcing an occupational shift in his life-course. On recent visits he seemed lost and wistful, sitting in his chair chain-smoking. It is as if he had lost his "destination and map", to use Frank's (2004:304) term, who suggests that through the process of storytelling about their experience, sufferers can "learn to think differently and construct new perceptions of [their] relationship with the world".

After TB, time slowed for Dennis and he lamented his loss of reserve as a seemingly permanent condition. "Now I'm ten and a half stone, I've lost strength; I used to be a very strong person ... since my treatment I can't get back to square one". Square one is the elusive equilibrium that in the past allowed him to enjoy drinking and withstand long, seven day working weeks. He first managed to overcome tuberculosis as a young person and regained his strength after a lobectomy (surgical removal of part of the lung) and nine months bed rest as part of two years in a sanatorium. "I wish there were the drugs then that there are now", he said. Second time around the changes that have occurred for Dennis are not proving to be reversible, and he is required to adapt to the uncertainty that has altered his former self-image. Identity dilemmas can occur for men who are challenged to accommodate uncertainty and loss caused by the experience of illness that challenges their masculinity (Charmaz 1994). The despondency that Dennis shows is associated with not being unable to "recapture his past self" (Charmaz 1994:279) that reflected values he still holds dear. During my conversations with Dennis, despite his 75 years, I noticed that the only reference he made to his age was when describing the experience of TB in his youth. In other words, he does not associate his health issues with aging. His notions of

health were connected to work, to being productive or functional and they also align with his political economic explanation about tuberculosis (see Chapter Four).

In hearing Dennis's narrative I was aware of witnessing his suffering that is normally kept so private, of him being "no longer available to [himself] in the old terms" (Charmaz 1994:279). I talked to him about the value of writing his story of young life in a sanatorium and offered to send him a copy of *Bread and Roses*, the autobiography by Sonia Davies who had TB when he first did. The challenges that occurred for Dennis and others led an altered identity, and an evaluation of life values.

By contrast David, at the age of 47 years, managed to continue his work by moving his office to his home. This has facilitated continued work on his project, although at a slower pace, and because he works with his friends, they have adapted to hold meetings at his flat. This means that when tired he can rest, "sometimes in the afternoon [when] I think I'd like to go and lie down for half an hour or something". A process of "normalisation" as a method of managing illness "entails either acting as if illness has no impact and thus putting it between parentheses, or else integrating it into one's life" (Bury 1982 cited in Pierret 2003:9). David was fortunate that he did not experience side effects during the one year treatment. At the outset of the illness as mentioned before, he postponed major work commitments for a year, and indeed one year hence he is pursuing a major new career opportunity.

The above stories exemplify two very different outcomes of TB of two men aged almost thirty years apart whose illness experiences show stark differences in biographical disruption. Their variable experiences of illness are different due to the coexistence of other illnesses, in part due to their age.

Biomedicine and Cure

As biomedicine aims to treat a specific disease that often has a singular cause, involving body processes, a successful outcome is known as a cure (Strathern and Stewart 1999). In this reductionist process, Kleinman (1995b:31) contends that the patient's experience of suffering is denied. As a disease oriented model, biomedicine seeks to cure the cause of TB with multiple powerful drugs. The work of [Armstrong {, 1995 #445}](#) traces the development of Western Medicine and describes the phase of Laboratory Medicine that developed at the end of the nineteenth century [{Jewson \(1976\) cited in\Armstrong, 1995 #445}](#). The laboratory has become both the site of analysis of body products in the absence of the sick person and in turn it is where many agents of cure are produced. This pivotal

role of the laboratory as the site of diagnosis and decision-making that affect the sufferer was portrayed earlier by participants who were anxious to leave hospital but were constrained because they had to ‘get their count down’. The sufferer need only produce the sputum for testing; so that the embodiment of tuberculosis disease for the sufferer was selectively reduced to the laboratory results of ‘the count’ by medical management. The art of healing was associated with an earlier phase, Bedside Medicine, whereas Laboratory Medicine is disease oriented, toward a technical cure of disease {Armstrong, 1995 #445:194}.

Healing based on the restoration of reserves of health is not part of the biomedical paradigm and it is therefore clear that doctors and their patients are often “talking past each other” in their expectations of the outcome of therapy. The sick person carries an expectation that a cure of the disease, in short “killing off the microbe” will end their suffering and allow them to “get back to square one”, to their former sense of wellbeing. They expect to feel healed (Spector 2000:20). This after all is unsurprising if we consider prior experience of the sufferer in using antibiotics for lesser ills may have allowed a complete feeling of recovery. One participant elaborates this

“we all get a cold sometimes, or maybe a flu or a cut finger, and its two or three days or a couple of weeks of inconvenience, but you’ve done your medication and you’re better again and you are off cycling or whatever ... serious illness, suddenly you realise you can’t do it, you may be determined you’re going to ... and suddenly you actually hit the wall, and you can’t fight your body.”

The medical approach to cure is disease centred and particularly for a tenacious infection such as TB, the treatment aims at the bacteria, to eliminate them by virtual overkill to be sure that no dormant bacillus remains. According to (Kleinman 1995b:31) the practitioner is constrained by biomedicine to view the experience of the illness from a narrow perspective that objectifies the subjective experience of suffering for the sufferer and their family. The sufferer is dehumanised in the construction of the disease process but the clinician is also constrained to embark on a meaningful explanation “with both hands tied behind the back”(Kleinman 1995b:32). The outcome has been described by Kleinman as “Disease sans Suffering” and “Treatment sans Healing”(Kleinman 1995b:31). Obviously for the sufferer, the embodied illness experience is fuller. What counts as symptoms in a medical consultation constrains what is appropriate to tell (Frank 2004:305). In consideration of Kleinman’s doctor’s perspective there is a dilemma for both parties that derives from where each stands in the therapeutic process.

Talking Past Each Other.

The differing goals of doctor and patient brings to mind a local anthropological concept, “talking past each other” (Metge and Kinloch 1987:8), that was developed to describe the cross-cultural interactive process when parties assume their understandings and values are universal. Although both patient and doctor have good intentions, when each operates from within their own explanatory model, and these models are not congruent, misunderstandings, disappointments and frustrations may result. The patient is ‘cured’ of the disease but in his/her own terms, is not better, not back to normal. The hope engendered by having a disease with a cure is reflected by Frank: “All the things I couldn’t do, but I had hope because I knew if I did what I was told, took my medicine *I would be better.*” Here the moral overtone of doing the right thing by the medical experts, subjecting oneself to their control, comes with the reward of a cure. Hope is also instilled by PHNs in those undergoing the long process of tuberculosis treatment, through careful management of dialogue about what lies ahead.

Healing as the Restoration of Reserves.

Most participants viewed the cause of their illness in terms of explaining how their reserve of health became depleted, thus allowing the tubercule bacillus to gain ascendancy. Frank began his narrative by stating that he was “actually very fit” and “somehow the TB came through my immune system” because “my defences were low at the time”. Dale put his recovery from extensive TB disease down to his “good constitution”

As sufferers described in their explanatory models, the causes of their TB illness were multiple and drew on their life history leading up to illness (back to an earlier life-stage, for some who first contracted TB in their youth). Therefore I argue that a return to wellness depends on signs of the reserve “being back to normal”, over and above “not having TB”. For some participants, the completeness of their healing was signalled by a return to everyday activities or pleasures of life enjoyed before TB (drinking alcohol was a popular one). As mentioned earlier, the signs of wellness that participants commonly found elusive after TB were a weight gain to pre-TB levels and an associated good appetite and a disruption to the pleasures of alcohol.

Participants spoke of body weight as if, in order to ‘top up’ reserves of health they needed a certain weight ‘to come and go on’ and this required a good appetite. A perception of the body in balance as reflected in adequate body size and weight runs contrary to popular notions of wellness revolving around a body image that idolises

thinness. Recent research conducted in Northern Italy about perceptions of health and body function of local people aged mainly in their 30s and 40s shows a concern with balance, because “thinness denotes a loss of vital force, a meaning that was very significant in the disease conditions of the past” (Whitaker 2003:351). The notion of a lost “vital force” sits well with the concerns about weight and appetite of TB participants after treatment that was not shared by their doctors.

To be healed is to return to health that is conceived as a reserve of health for many of these Pakeha participants.

Treatment Vigilance

A tension exists for the TB sufferer between what their body is telling them and the biomedical explanation that insists a complete cure means “to keep on with the drugs” for the prescribed time. In biomedical terms it is only then that a cure is affected. This is an ongoing challenge for the sufferer and their PHN who must watch to ensure that medication is swallowed, juxtaposed with initiating and sustaining a friendly supportive relationship, despite the initial reluctance of some sufferers to undertake a long regimen of medication. A relationship of partnership is sought by PHNs with their clients. However, the inherent judgement and power inequities of DOT make an equal partnership relationship elusive. An alternative model may be one of participation.

The process of implementation by PHNs is crucial to the success of DOT. The interpersonal relationships that they seek to build with their clients over long periods of treatment as an inclusive part of the clinical care they provide are the key to successful treatment. Notions of care vary, as demonstrated by Fitzgerald (2004), however nurses identify strongly with this component of their work that is difficult to quantify. Care is described by Fox (2000) as having two aspects that exemplify the aspects of care that public health nurses are concerned with in the supervision of tuberculosis therapy. These are the vigil of care, and care-as-gift. The *vigil* of care (a term used by Florence Nightingale) is closely related to the knowledge/power that the nurses bring to their work as they practice care and control of people undergoing treatment in the community (Fox 2000:333). The disciplinary aspect of DOT as surveillance was overlooked or normalised by most participants who keenly remembered the interpersonal alliance they established with their nurses as central to the care they desired. This aspect of care that is concerned with “love, trust and giving” (Fox 2000:336) has been denoted *care-as-gif* and was derived from the work of Mauss who described the reciprocal relationships that imbued

obligation to the other, about who takes on the label and role as patient or client. The long term relationship that is developed over the course of treatment with the PHN has been likened to that of a friend or part of the family by the parent of a sick child with TB (Miller 2001). If the care and concern is felt to be genuine and holistic then a sense of indebtedness is felt by the receiver to reciprocate by adhering to their treatment program.

Care

Care is a human need in times of suffering and the care aspect of DOT when it is sensitively carried out makes a strong contribution to the success of treatment. Control of tuberculosis is the central aim of public health interventions surrounding TB and I agree with Ogden (2000) who makes the point that control is a disease focussed medical goal but is not the central concern of TB sufferers who confront TB amidst their everyday lives. Care is a vital ingredient in the restoration of feelings of health and wellbeing that sick people associate with being healed. The technological changes taking place in hospitals and clinics has reduced the “tenderness of persons” (Dew and Kirkman 2002:229) that people crave when their lives are turned upside down by serious illness. The information technology changes that are ongoing in the documentation of patient information in Auckland health care has been shown to distract the medical personnel from interaction with the sick person in favour of trying to “bring the results up” on screen. As Dew and Kirkman (2002:230) note, “introducing technology in any workplace alters the practices and activities of those working there”. Therefore it is vital that nurses provide supportive care for vulnerable TB sufferers during the course of their therapy if successful outcomes are to be maintained (Ogden 2000:138).

As I consider the apparent adherence that all participants had to their treatment, I am aware that to my knowledge none of them recalled the provision of treatment under DOT invasive of their privacy and self-responsibility. As Foucault has argued, power is most effective when it is hidden from view, and in the social relationship between PHN and client during DOT it is effectively hidden from view.

The PHNs concerned with the Pakeha participants are mature women, who form a stable staff and in these cases were of the same ethnicity as their clients. One participant put the level of care and expertise he encountered while hospitalised, in the clinic and in community care, down to gender. He espoused,

The place is run by women, the doctors are there but it's the women who know what is going on. Even in the ward on the doctors' rounds,

everything the doctor was told about me came via the nurses, they knew what was going on for each patient.

There is no doubt that nurses in the hospital and the community setting manage diverse roles to bridge the distance from medical management of TB and the sufferer's experience of living with the disease.

Social causes of disease are concealed in the preoccupation of biomedicine with individual blame in the form of non-compliance with medical orders. DOT provides a technical solution in which surveillance and power can be veiled in a caring personal relationship managed masterfully by nurses.

As an overt method of surveillance of the sick person, DOT acts to produce a compliant docile sick person who is able to be rapidly reconstituted back into their functional roles in the shortest, most cost effective time (with minimal hospitalisation). The effectiveness of DOT strategies for the sufferers I followed was greatly aided by the long term in-depth social relationships that Public Health Nurses form with their clients, rather than the observing aspect of the DOT therapy. This was further extended by the cultural congruence between PHNs and participants in this study. There has previously been little attention paid to these aspects in TB research, as there has been a variation in DOT success rates and little breakdown of the elements of DOT (as single or simultaneous factors,) that promote successful treatment outcomes.

However Volmink and Garner (2000:4) contend that there are indications so far that patient centred care that accommodates the "needs and preferences of patients seems to lead to more satisfied patients. The quality of interaction between patients and supervisors may, however be a key factor in explaining these results, and DOT less relevant." Similarly in her review of adherence to TB treatment, Sumartojo (1993:1315) cautions that the DOT treatment regimen must also "recognise the needs and dignity of patients". The success of the New York City DOT intervention for TB must be considered in the context of the "creative array of services" implemented with DOT that provided

an individualised patient treatment plan that also provided accessible services , a reliable source of medication, treatment in a variety of settings, social services, and an integrated system of follow-up ... Such an array of services provides an operational definition of compassion in health care and shows how supervised therapy can be used as a positive rather than a punitive intervention for patients. (Block *et al.* 1994:456)

The implementation of DOT in this setting sounds rather like the patient centred approach that the participants in this study valued.

In his book, *Contagion and Confinement*, about the historical management of TB in Seattle Barron Lerner (1998) also discusses the popular attention provided by DOT. He quotes a person on DOT as saying, “I definitely needed medical therapy but I also definitely needed the attention I was getting. It built up my self-confidence. That’s what really made me complete therapy” (Lerner 1998:168). Medical anthropologists Good and Good (1981:178) say that whatever the pharmacological or physiological treatment effect of “rational (biomedical) treatment the therapist’s ability to influence the patient’s reality, to combat demoralization and construct new realities, is a powerful healing force”. In the experience of the Pakeha participants the method of DOT delivery by experienced nurses provided humanistic care, a latent effect of this global policy that is not a requirement. These social aspects of care that accompany sensitively delivered DOT are difficult to measure but require further evaluation.

DOT, a Standardised Model

As a ‘brand’ DOT is not just about observing the swallowing of medication, this is merely one aspect of the policy developed by WHO and adopted by many national governments as part of global health policy (Ogden *et al.* 2003). Ogden *et al.* (2003:10) caution the wisdom of a “one size fits all” strategy that determines World Bank funding and has the potential to “harm locally appropriate programmes”. Similarly Garner and Volmink (2003) stimulate discussion toward alternatives to the direct observation method citing trials in countries with a high incidence of TB that show no advantage over self-administration. 4(2003:82) contend that observation is essential; they propose that DOT should not resort to supervised swallowing. While DOT is set up as the only ethical strategy, research into other methods is not encouraged. There are multiple conflicting opinions about wholesale DOT as the core of WHO policy.

The normalisation of treatment for tuberculosis is directed by WHO, however it appears that in New Zealand the treatment length is managed by clinicians on an individual basis according to the severity of the episode and type of bacillus involved. Note that the DOT regimen is a technical cure and there is no provision for patient care (Lienhardt *et al.* 2003:202, Waitzkin 1981:342). In fact the manner of implementation is not specified in DOT, in third world countries many patients must make their own way to a clinic for DOT whereas for most TB sufferers in New Zealand the healthcare system facilitates the

medicine to be delivered with a care component by professional carers. I question how the success rates of these two methods of the same model can be compared globally. However DOT is employed selectively in New Zealand and is used for half of those under TB treatment. I have discussed earlier the decision-making process that hospital clinic and public health practitioners undertake to decide on the method of treatment delivery for each TB sufferer. The fact that all of the participants adhered to treatment is due in part to selection bias and for a truly effective study of compliance issues it would be ideal to meet with those who were non-compliant. However on the basis of this research that includes attitudes to health and illness of sufferers and 'well' Pakeha, participants' experiences of TB and community attitudes, there are some assertions that can be made.

As was clear in the conceptions of health and illness of paired participants and the explanatory models of TB, Pakeha cultures of health are immersed in the biomedical epistemology that provides mainstream healthcare. This aids the access that Pakeha have to healthcare as they are culturally congruent with the culture of biomedicine. This facilitates effective communication with healthcare providers and information about tuberculosis that is offered is generally understood and taken up in the explanatory models of Pakeha with TB.

Networks of Care.

A high incidence of TB in the elderly age group has consequences for the level of care required in the community that sometimes includes assistance with transport to clinic and networking with other agencies involved in care at home. The aged participants had social networks that 'watched out' for them but did not always have family members who were able to facilitate their weekday clinic visits. In Rose's situation a family member rearranged their home circumstances to accommodate her and when this was no longer successful alternative appropriate accommodation was arranged. The experiences of people overcoming TB demonstrate the far reaching effects that the disease and its long treatment has on the lives of the sick person and their social network members who strive to be supportive. In the midst of everyday life TB is to be managed by the sufferer and their family amid other demands of daily living over a period of a whole year. Nevertheless today's treatment brings more certainty and lesser biographical disruption than the social exclusion of long term sanatorium treatments that some of the participants experienced. However elderly people have generally struggled to return to their former levels of health and feel considerably set back by the experience of TB this time around.

Conclusion

It is clear that personal experiences of the treatment of tuberculosis are not homogenous, they are affected by a variety of factors such as the participant's age, having had TB previously, socio-economic status, other health conditions, social networks, conceptions of health, the severity of the disease, a timely diagnosis and their vulnerability to stigma. The social suffering experienced by those already marginalised by society has been exacerbated by the stigma and physical effects of the disease. Although Pakeha do seek biomedical advice, albeit with the help of social networks, some of the participants in this study still experienced diagnostic delay. I argue that the nature of stigma surrounding TB from the perspective of many Pakeha contributes to the invisibility of tuberculosis for this group that can be linked to diagnostic delay, a problem that can have drastic consequences for the elderly. The aftermath of tuberculosis cure varied according to the age, social status, pre-existing health issues, economic position and expectations of treatment. For many participants, the expectations of a return to former reserves of health were not met although they were successfully cured. The narrow focus on pharmacological solutions alone at a global level has supported the development of the DOT treatment regimen that arose from a singular attention to patient compliance. This ignores continuing structural problems and, in this instance, human elements of caring for sick people. My research with Pakeha people with TB suggests that the professional care provided by PHNs in their delivery of DOT and monitoring of self-medication is vital to successful treatment outcomes, in terms of care, and goes some way towards promoting healing and acceptance of a post-TB status.

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