Multiplying and Dividing brings together the work of two multi-disciplinary research groups located in Canada and New Zealand who discovered that they were working along similar lines in their research on historical and contemporary tuberculosis in their respective countries. The volume, the outcome of a joint workshop in Canada in 2006, shows the multiple realities that make up the experience of TB for nations, communities, and individuals. TB can divide communities, but in some circumstances unites them in a quest for its eradication. The social and epidemiology research undertaken into TB exposes social divisions and inequalities in these two postcolonial societies.

Part 1, comprising six articles, addresses dimensions of contemporary public health approaches to TB, Part 2, comprising five articles, analyses historical policies that contributed to disproportionately high levels of TB among indigenous people in both nations, and Part 3, five articles, presents experience-near accounts of individuals, families and communities coping with TB in daily life. The individual studies speak to the power of ethnography and ethnohistory in analysing infectious disease and the societies in which it exists.

Participants in the “History, Political Ecology and Colonial Experience of Tuberculosis in Canada and New Zealand” Workshop, McMaster University, Hamilton, Ontario, June 7–9, 2006.
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The University of Auckland acknowledges the contributions of all authors. This publication has been peer reviewed, and all reasonable efforts have been made to ensure the accuracy of the materials published herein.

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<http://fhs.mcmaster.ca/healthcarehistory/places/chedoke.html> Accessed 22/11/07
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Introduction

This volume, *Multiplying and Dividing: Tuberculosis in Canada and Aotearoa New Zealand*, grew out of a transdisciplinary workshop of academics, graduate students, and health care professionals from Canada and New Zealand, held at McMaster University in June 2006. Earlier, we had become aware that there were two research projects in our respective countries whose focus was on tuberculosis from a social perspective. Our rich and fruitful dialogue – which led to the workshop and to this volume – began in Aotearoa New Zealand in February 2005 when the “Political Economy of Tuberculosis” team brought to Auckland members of the “Three Centuries of Tuberculosis among Western Canada’s First Nations” project to discuss our projects and exchange ideas.

We discovered that our projects had much in common. Tuberculosis is a major global health problem, but both Aotearoa New Zealand and Canada are fortunate to experience relatively low national TB rates (11/100,000 and 5/100,000, respectively) compared to global standards. Although both nations have been successful in lowering the incidence of TB, the disease has yet to be eradicated from either of these wealthy nations. In fact, the very success in controlling tuberculosis may actually make both nations vulnerable to a certain level of complacency and neglect (Paluzzi 2004). When diseases like TB are allowed to ‘hide’ among the more vulnerable and disenfranchised members of society, the importance of the problem fades (Farmer 1999:200-1). In fact, while rates may be very low for the general populations, this masks the reality that TB is rooted in pockets of marginalised communities in both nations. Individuals and communities suffering from it often bear overlapping burdens of other diseases, coupled with adverse social conditions, rendering them multiply burdened (Singer and Clair 2003).

Our two projects also shared the view that tuberculosis is a sign of social and political inequality and that disproportionately high rates of tuberculosis in particular communities are the surface expression of underlying inequalities. Both projects were asking questions about the impact of colonialism, government policy, medical practice and authoritative writing on marginalised groups suffering from tuberculosis in our respective countries. Canada and New Zealand share a history as former British colonies and as members of the Commonwealth of Nations. Both are characterised by cultural, economic and political diversity fuelled by immigration. Some of the immigration streams are from similar parts of the world, such as the Horn of Africa and parts of Asia. Both nations have indigenous populations – Maori, indigenous people from other Pacific Islands now resident in New Zealand, and First Nations, Inuit and Metis in Canada – that suffer an excess burden of tuberculosis, as do immigrant and refugee communities in both nations. At the same time, the two research groups were working within a variety of methodologies and theoretical paradigms, including political ecology and syndemics, and within historical and contemporary frameworks. In addition, the workshop provided a place for frank exchanges about research methodologies and for participants to share research experiences. We discovered how multiple methods of ethnographic, ethnohistorical, discourse, archival, epidemiological and spatial analysis are enriching social research on tuberculosis in both nations. There was much to be learned from this prism of perspectives.
The workshop

Our productive and stimulating initial exchange of ideas in Auckland motivated a follow-up workshop in June 2006 at McMaster University. Twenty-three participants from anthropology, geography, history, politics and public health came together to discuss our research over a three-day period. We explored more fully the commonalities and divergences in the histories of the two nation-states that encouraged, and continue to encourage, tuberculosis to flourish in indigenous and immigrant communities. TB reveals the fault lines of societies, highlighting structural inequalities that persist from the past into the present. Detailed contextual studies of the experiences of First Nations, Maori and Pacific peoples highlighted the shared and unique aspects of the complex history, social context, and geography of this disease, as well as its links to indigeneity and marginalisation in the two nations. We examined the processes and policies that contribute to high rates of tuberculosis in other marginalised groups in both nations, such as elderly Pakeha in Aotearoa New Zealand. Equally important, we scrutinised the ways in which discourses on immigration and immigrants (‘contaminating others’), indigenous people (‘dying races’), coupled with surveillance by health care providers and medical institutions, serve to pathologise not only the bodies but also the identities and social networks of individuals and groups characterised by high rates of tuberculosis.

We also shared understandings about the many ways in which this pathologisation plays out in the experience of daily life, including barriers to treatment, and how particular circumstances gave rise to particular biologies, to particular tuberculoses. We examined the tensions between the goals of institutions and rights of the individual, intangible barriers to care, and exclusion of individuals, all of which are challenges to successful public policy in the area of TB. The study of historical institutions, such as sanatoria in Aotearoa New Zealand or the Native Residential School System in Canada, offered a comparative perspective from which to explore other links between public policy and tuberculosis. We delved into the complex underlying policies and processes that caused tuberculosis to multiply in some communities in our respective nations, and simultaneously divided them from the rest of the nation through fear, stigmatisation, and distortions of identity. The hidden costs of tuberculosis are often forgotten: isolation, personal devastation, fractured families and hollowed out household economies.

At the same time, the workshop discussions reinforced our conviction that there is no single, generic tuberculosis experience. If tuberculosis rates are to be reduced at the international, national and local levels, it is necessary to adopt an interdisciplinary approach that allows each of the complex and interrelated forces responsible for the spread and maintenance of the disease in particular communities to be addressed. Such collaborations are required to develop culturally appropriate prevention and treatment options for individuals and communities most in need. Since each group’s knowledge, awareness, and perceptions of TB are moulded by their lived experience, it is important that TB programmes operate at the community level. This necessitates taking into consideration cultural beliefs and risks associated with TB (explanatory models), root causes of stigma(s) associated with it, and health seeking behaviours. It calls for a clear understanding of barriers to TB treatment and prevention efforts as well as attention to structural causes of social and health inequalities. The effective control of TB appears to lie in culturally appropriate, sustainable and non-stigmatising interventions that build upon the best of Western scientific and indigenous/immigrant knowledge and at the same time improve the overall quality of life for people living with TB or at risk of contracting it.
This volume

This collection of articles, then, is the product of that workshop and of the coming together of two disparate research projects, joined by a common theme (tuberculosis) and by social science perspectives. In constructing the three sections that make up the volume, we have tried to respect the dialogues between researchers that occurred at the workshop. Each section is prefaced with a short introductory explanation that highlights the major themes that link the papers to each other, and to others in the volume. However, we encourage other groupings of the articles along other thematic lines that more closely match individual research interests, as made possible by the e-publication format of this volume.

The volume begins with *Unpacking Tuberculosis*, a set of six articles that addresses contemporary public health approaches to tuberculosis. Thornley and Pikholz lay out the epidemiological landscape of tuberculosis rates in Auckland, Aotearoa New Zealand from a contemporary public health perspective. Barta argues that public health investigations of tuberculosis in families should include the entire domestic ecology, including pets that may transmit or acquire tuberculosis from their human companions. Littleton and King take apart the underlying local ecologies that reflect the history and current socioeconomic positions of ethnic communities in Auckland suffering from high rates of tuberculosis. Mavridis makes the case that neighbourhoods with high rates of tuberculosis in Winnipeg, Manitoba are multiply disadvantaged by overlapping social and health conditions that mutually reinforce and enhance each other. Park and Littleton show how ethnographic methods are needed to contextualise the community experiences of tuberculosis and counter the stigmatising effects of public discourses presented by media and political figures. Miller’s paper shows how stigma can be broken down by actively developing community partnerships that help to change the isolating effects of tuberculosis and improve access to health services. Oh considers the public policy framework within which health care is delivered to tubercular Māori in Auckland and concludes that it fails to live up to the fundamental principles of the Treaty of Waitangi. Farmer and Jacklin analyse research on TB in Aboriginal communities in Canada and call for more integrated and community level approaches to understanding the problem.

The second section, *Reproducing Tuberculosis*, presents a set of five articles that considers, at various levels of scale, the historical policies that contributed to a disproportionately high burden of tuberculosis among indigenous people in Canada and Aotearoa New Zealand. Padiak sets the scene through her discussion of the reasons for the decline of tuberculosis in Europe, as illustrated by British military records. The first worldwide tuberculosis epidemic wave, an outgrowth of the European epidemic discussed by Padiak, washed over Indigenous communities in Canada and Aotearoa New Zealand in the 19th and 20th centuries. Hackett takes up the problem on a regional scale by examining how disparities in rates of tuberculosis emerged among Aboriginal groups in western Canada. Stephens scrutinises tuberculosis at the community level, focusing on Walpole Island First Nation. Stoops considers how tuberculosis spread among children attending the government-mandated residential school at Norway House Cree First Nation. Finn’s paper reveals that high rates of tuberculosis among Māori are the outcome of a constellation of interacting social pathways in the first half of the 20th century that served to focalise infection, and ultimately TB disease, among them.
The last set of articles, *Living with Tuberculosis*, throws the spotlight on individuals, families and communities dealing with tuberculosis in daily life. Dunsford’s study of TB in 1940s Aotearoa New Zealand reveals both the complexities of the disease at that time and the continuities into the present of social divisions that marked marginalised communities with higher TB rates in the past. Searle uncovers the shock and stigmatising experiences of Pakeha in Auckland diagnosed with tuberculosis. The papers by Anderson, Lawrence and Ng Shui take up the problem of the stigma of tuberculosis among immigrants in Auckland from Asia, African refugee and Pacific communities. The meanings and forms taken by stigma may differ in these communities, but the outcomes often include loss of social support, diminished community building, and difficulty accessing the medical system. Ironically, while immigrants are frequently blamed for the “TB problem” in Auckland, they often acquire the infection and disease after migrating and, in the case of some Pacific communities, have higher rates than are recorded for their home islands.

The title “Multiplying and Dividing” was inspired by Mol’s (2002) study of the multiple ways in which one disease, atherosclerosis, is enacted in a hospital setting. The papers in this volume similarly approach TB in the multiple ways determined by the different disciplines of anthropology, epidemiology, history, geography and political studies as well as the multiple ways in which communities affected by TB enact it. These stories from small places reveal that the disease of tuberculosis is best understood in the particularities of its local expression, not as a single disease whose face is the same wherever it occurs. Yet these numerous versions of TB from different times and different places disturbingly demonstrate that the power of TB in the past to create fear is not lessened by its current status as a treatable condition. TB still has the power to divide, to recreate “the archaic idea of a tainted community that illness has judged” (Sontag 1990: 134). It is the role of those working with infectious diseases like TB to point out that transmission of the bacteria and conversion of the infection into active disease are not inevitable consequences of particular lifestyles or of immigration of particular groups. They result from particular ecologies we create for disease.

References


Notes

1 New Zealand Health Research Council 2002-2006 ‘The Political Ecology of Tuberculosis in Auckland’


3 Royal Society of New Zealand ISAT Fund and University of Auckland Research Committee International Strategic Opportunities and Research Collaborations Fund.

4 Funded by Social Sciences and Humanities Research Council of Canada Aid to Research Workshop Grant #646-2005-1014; Canadian Institutes for Health Research, through the Indigenous Health Research Development Program at the University of Toronto and McMaster University; Department of Anthropology, McMaster University; University of Auckland Research Committee International Strategic Opportunities and Research Collaborations Fund.
Tuberculosis is a significant issue in itself as well as a potent indicator of a population’s health, the role and effectiveness of the public health system, and the state of underlying social and economic conditions. This potential when studying TB to focus beyond the bacteria and the patient is apparent in the group of papers in this section which demonstrate the multiple ways of analysing tuberculosis.

The section begins with a detailed epidemiological analysis by Thornley and Pikholz of the Auckland Regional Public Health Service. They examine the incidence of TB in the single urban location of Auckland, New Zealand, demonstrating that despite New Zealand being a low incidence country (less than 20 cases per 100,000 per year), the rates mask major differences by ethnicity and place of birth (whether foreign or native born). These marked ethnic differences are confounded by other factors of inequality (economics, geography). In addition, for some families, place of birth, place of residence, and ethnicity may be very fluid categories given the transnational nature of many people’s lives (as demonstrated in later chapters by Ng Shui and Anderson).

While Thornley and Pikholz’s paper focuses on the contemporary and human public health problems associated with TB, Barta points out how our focus on humans misses an important aspect of many domestic ecologies: the role of pets and other animals. Her starting point is the discovery of a dog skeleton with evidence of TB dating to the 16th century in Western Ontario. The dog was identified as having a chronic pathological condition caused by TB infection. From a distance of centuries, she reminds us that dogs and cats and other domestic animals may act as reservoirs of disease or as recipients of disease among humans. It is a timely reminder that domestic ecologies do not necessarily involve only *Homo sapiens* but that there may be a real advantage in broadening our attention to the animals that share human lives not just in historical or archaeological studies (e.g., Matisoo-Smith and Robins 2004) but also in contemporary populations. Barta’s work on domestic animal health as a sentinel of TB in a household is a striking parallel to recent analysis suggesting that pet abuse can be a sentinel of child abuse within the same household (e.g., Ascione 2005).

The remaining papers in this section serve to unpack in many ways the epidemiological pictures presented by the first authors, demonstrating not only how TB can be explored through multiple lenses but also the multiple lights that TB throws upon the rest of society. Littleton and King argue that the ethnic differentials analysed by Thornley and Pikholz are signals of underlying local ecologies which reflect the history of particular communities within Auckland as well as their current socioeconomic situation. These local ecologies are not just related to the transmission of TB and its incidence but also reflect the experiences of those with TB. From the maps of TB incidence it is possible to read the experiences of communities: the issues of isolation and transport are particularly apparent.

Mavridis uses a similar basis of geographical distribution to point out that an alternative or complementary approach to the idea of local ecologies is to focus on *syndemics* – the notion of “two or more afflictions interacting synergistically, contributing to excess burden of disease in a population” (CDC 2007). She discusses the possibility that infectious diseases such as TB are operating in unison with other effects of inequality including low birthweight, literacy, and low levels of immunisation. All such synergies have the power to create long legacies in
disadvantaged sectors of the community. In Schell’s sense (1997), the syndemic approach presents an opportunity to analyse how risks focus into particular parts of society and become perpetuated within them. While the Political Ecology of TB in Auckland project has explicitly focussed upon TB as a mirror for any number of infectious diseases (e.g., STIs, meningococcal B etc), Mavridis demonstrates another way of exploring ecological links by looking for the connections between the myriad social and health conditions. In the former case one stands for many, in the latter one becomes many.

The work of anthropology, however, is not just exploring the conditions but questioning what to do with that information. Park and Littleton, working on the Auckland project, take one of those burning issues to do with TB, that of immigration, and show how the epidemiology and local ecology (described in the earlier paper) is constructed by media and political figures in particular ways that serve to further isolate and marginalise immigrants and their families. They argue that statistics need to be contextualised with ethnography but that there is also a further step moving beyond data into a public anthropology where that nexus of epidemiological, ecological and ethnographic data is used to drive awareness of the stigmatising effects of public discourse.

Miller’s paper shows the other end of the cycle. While Park and Littleton draw attention to larger social forces, Miller shows how stigma can be attacked at the level of the community. Her paper stands in counterpoint to Thornley and Pikholz’s discussion of epidemiology by showing the other end of Public Health activity: health promotion. She describes a project developing education and attitudinal change not just in communities but also the health force. The approach advocated in her paper goes beyond just providing information to actively engaging and motivating community action with the aim of developing their active engagement with the health system. While the preceding paper is aimed at changing the bodies politic and social, Miller’s approach is concerned with encouraging individuals and, through individuals, communities, to become active players in changing attitudes and especially destigmatising TB both within and beyond that same community. Given the stigma associated with TB both historically and in contemporary societies, the public work advocated in the last two papers is a crucial responsibility for those researching the disease.

However, as the title of this volume suggests there are multiple TBs (Mol 2002) and Oh’s paper reminds us that TB is not just a lens onto population health but the operation of health systems and in particular the conduct of health policy. Through her interviews of Maori with TB, Oh explored the extent to which the principles of protection, partnership and participation distilled from Treaty of Waitangi (the treaty between the Crown and Maori) are achieved when a disease seen as a public health imperative is involved. Her work reminds us of the gap between policy and practice and, in addition, that health is affected by externalities beyond the health system: family relationships and transport are two obvious factors. The principles underlying policy are far removed from the day to day experience of those with TB.

Despite the diversity of approaches to the study of TB seen among the papers in this section the final paper by Farmer and Jacklin reminds us of the need to continue to push for integrated approaches to the disease. Their analysis of Canadian research undertaken on TB among indigenous people demonstrates that the biomedical approach continues to predominate and that there is a lack of work explaining why and how some indigenous communities are still vulnerable to TB. It is a reminder to all of us that the burden of TB is disproportionately felt by some in every nation.
References


Chapter 1
Patterns of Tuberculosis Epidemiology in Auckland, 1995-2006
Craig N. Thornley and Cathy Pikholz

Tuberculosis (TB) remains a major cause of illness and deaths globally. In 2005, an estimated 8.8 million people around the world became sick with TB, and 1.6 million people died with the disease (WHO 2007:1). TB is also globally the leading cause of death from an infectious disease (WHO 2004). The World Health Organization (WHO) estimates that in 2005 TB incidence rates were stable or in decline in all WHO regions of the world, however the total number of new cases was still rising due to increasing case-loads in the African, Eastern Mediterranean and South-East Asian regions (WHO 2007:1).

The trend in the number of new TB cases in New Zealand has been increasing significantly since the mid-1980s, although when adjusted for the size of the New Zealand population the disease rate has been static at around 10 cases per 100,000 population annually (Das et al. 2006a:1), low by world standards (Dye 2006:938). The persistence of TB in New Zealand at this level has been attributed primarily to migration of TB infected people from high-incidence countries, a proportion of whom have subsequently developed active disease (Das et al. 2006b:8).

The Auckland region is the most populated and most culturally and ethnically diverse region in New Zealand (Statistics New Zealand 1999:9). It is arguably the gateway to New Zealand and contains the only truly large New Zealand city (Pool et al. 2005:36). The Auckland region also contains the highest TB burden in New Zealand: two of the three Auckland region District Health Boards (DHBs), Auckland DHB and Counties Manukau DHB, held respectively the highest and second-highest DHB-specific TB rates in New Zealand in 1995-1999 and 2000-2004 (Das et al. 2006a:3). In 2006, 43.3% of the total New Zealand TB disease cases were notified in the Auckland region (ESR 2007:56). An understanding of the epidemiology of TB in Auckland, the last published review being for the 1992-93 period (Calder and Priest 1996:164), is important in developing TB control policy for New Zealand as a whole.

Methods
Data for calculating the trend in TB crude incidence rates for the years 1948 to 2006 were drawn from annual reports of the Director-General of Health and population information from New Zealand official yearbooks published by the Department of Statistics (now Statistics NZ). Data for the detailed analysis of the period 1995 to 2006 were drawn from information routinely collected on patients diagnosed with TB and notified to medical officers of health (MOsH) in the three Auckland region health districts: northwest, central, and south Auckland. Under the Tuberculosis Act 1948, medical practitioners are required to notify patients diagnosed with active TB to the local MOsH. The information collected at initial notification is verified and supplemented by direct patient interviews conducted by public health nurses, and from clinical summaries forwarded by treating clinicians. Notifications are compared with reports, forwarded by the regional TB laboratory, of laboratory tests suggesting TB in Auckland patients: doctors of patients who have not been formally notified are contacted and notification solicited if appropriate. Data on cases included in the study were accessed from a computerised database held by Auckland Regional Public Health Service.
Cases of active TB disease were defined as patients with clinical specimen(s) either culture-positive for *M. tuberculosis* complex, smear-positive for acid-fast bacilli, with histology consistent with TB, or with *M. tuberculosis* nucleic acid; or patients with symptoms or signs (including radiographic examination) compatible with active TB disease and for whom full anti-tuberculous treatment had been commenced. Cases meeting this case definition were included in this analysis if notified between 1 January 1995 and 31 December 2006.

Cases were analysed according to sex, age, date of notification, ethnicity, country of birth, disease site, and drug resistance of isolate. Age was analysed using 10-year age bands. Trends in case notification over time were analysed either by year of notification, or by comparing notifications in the 1995-2000 period with the 2001-2006 period. Ethnicity was analysed using cases’ self-reported ethnicity, coded into five ethnic groups according to Statistics New Zealand definitions: Māori, Pacific peoples, Asian, European, and Other (defined as all ethnic groups other than Māori, Pacific, Asian and European). Cases with multiple ethnicities were counted in each ethnic group identified without prioritisation. Birthplace data were grouped into five regions by country of birth, as defined by Statistics New Zealand, and were further analysed as a binomial variable by birthplace either in New Zealand or outside New Zealand. Drug-resistance was analysed by presence or absence of resistance of the patient’s isolate to four first-line antituberculous agents: isoniazid, rifampicin, pyrazinamide or ethambutol.

Where appropriate, data were analysed as incidence rates, expressed as the number of cases per 100,000 person-years. Annual incidence rates were calculated by dividing the yearly total of notified cases by the mid-year population (estimated and published by Statistics NZ). If mid-year population estimates were not available for a particular variable or combination of variables, we used data from the nearest censuses, and estimated intercensal year populations using linear interpolation. The only exception to this was that data from the 2001 census was applied to the entire period for calculations of incidence rates by ethnic group and birthplace simultaneously. Ethnic-specific rates were not age-standardised.

Comparisons were made by comparing population-based rates or proportions for the variables of interest. Rate ratios were calculated by dividing the rate in one group by the rate in a reference group: rate ratios exceeding 1.0 indicate that the rate in the test group is greater than that in the reference group. Analysis of trends over time were made by calculating a rate ratio by dividing the 2001-2006 rate by the 1995-2000 rate. Rate ratios were tested for statistical difference from unity with the Episheet calculator (obtained from http://members.aol.com/krothman/episheet.xls, accessed 28/06/2006) that uses a standard method (Greenland and Rothman 1998). A 95% confidence interval (CI) was defined for each rate ratio.

Results

*Historic incidence rates*

TB annual incidence rates in Auckland declined overall from 1948 until 1987; thereafter, the annual rates have been consistently higher than the 1987 level (Figure 1).
Incidence of tuberculosis disease in Auckland, 1948-2006

**Incidence 1995-2006**

There were 2228 cases of TB disease notified in Auckland in the period 1995 to 2006 inclusive. A mean of 186 cases were notified each year, the annual total ranging from 242 cases in 2003 to 155 cases in 2006. Fifty notified cases died due to their TB, a case-fatality rate of 2.2%. The overall annual incidence rate of TB disease in Auckland was 15.1 cases per 100,000 population. The annual incidence rates significantly declined over the period 1995-2006 (chi-squared test for linear trend = 7.053; p < 0.01), however the average rate for the period 1995-2000 (15.6 cases per 100,000) did not significantly differ from the rate for the period 2001-2006 (14.6; relative risk [RR] = 0.94, 95% confidence interval [CI] = 0.86-1.02).

**Age and sex**

Age and sex information was recorded for 99.9% of cases. The annual incidence rate among males (15.9/100,000) was not significantly different to that among females (15.6/100,000). The majority of cases were aged between 20 and 49 years of age: cases in this age range account for 56.9% of cases among females and 50.4% of cases among males. The peak age-specific incidence rate among females was in the 20-29 year age group (26.2/100,000); however, the peak age-specific incidence rate among males was in those aged 70 years or older (34.1/100,000), as shown in Figure 2. The trend in age-specific TB incidence rate (Table 1) over time, as measured by comparing the 1995-2000 and 2001-2006 rates, varied significantly in only two age groups: the rate significantly increased among persons aged 20-29 years, and significantly decreased among persons aged 70 years or older. While the rate among those aged less than 20 years was stable between the two periods, the incidence in this age group in 1999 (18.3 cases per 100,000) and 2003 (16.0) was greater than the average annual incidence in other years (7.3).
Figure 2  Age-specific incidence rates of tuberculosis in Auckland, 1996-2006

Table 1  Trends in age-specific TB rates in Auckland, 1995-2006

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<th>Age group (years)</th>
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<th>2001-06 n (rate1)</th>
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<td>98 (8.7)</td>
<td>0.87</td>
<td>0.65 - 1.15</td>
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<td>20-29</td>
<td>207 (20.0)</td>
<td>297 (27.6)</td>
<td>1.38</td>
<td>1.15 - 1.65</td>
</tr>
<tr>
<td>30-39</td>
<td>201 (18.0)</td>
<td>220 (18.2)</td>
<td>1.01</td>
<td>0.84 - 1.23</td>
</tr>
<tr>
<td>40-49</td>
<td>127 (13.6)</td>
<td>144 (13.0)</td>
<td>0.96</td>
<td>0.76 - 1.22</td>
</tr>
<tr>
<td>50-59</td>
<td>109 (16.8)</td>
<td>105 (12.8)</td>
<td>0.76</td>
<td>0.58 - 1.00</td>
</tr>
<tr>
<td>60-69</td>
<td>98 (22.8)</td>
<td>97 (19.1)</td>
<td>0.84</td>
<td>0.63 - 1.11</td>
</tr>
<tr>
<td>70+</td>
<td>135 (28.5)</td>
<td>108 (20.8)</td>
<td>0.73</td>
<td>0.57 - 0.94</td>
</tr>
</tbody>
</table>

Note: 1 Rate per 100,000 person-years
2 2001-06 rate divided by 1995-2000 rate. A rate ratio exceeding one indicates an increasing incidence; conversely, a rate ratio less than one indicates a declining incidence over the period

Ethnicity

Ethnicity was recorded for 2220 (99.6%) of the 2228 cases in the dataset. Of these, 2201 identified with a single ethnic group and 19 identified with two groups. Overall, 1068 (48.0%) identified with an Asian ethnic group, 560 (25.2%) with Pacific, 213 (9.6%) with European or Pakeha, 204 (9.2%) with Maori and 194 (8.7%) with Other ethnicities. The ethnic-specific crude incidence rates were highest among those with Other ethnicity, at 123.6 cases per 100,000 person-years, followed by people with Asian ethnicity (57.4), Pacific ethnicity (30.5), Maori ethnicity (12.9) and European (2.3). Compared with persons of European ethnicity, the relative risk of TB among persons with Asian, Pacific, Maori and Other
ethnicities was 25.0, 13.3, 5.6 and 54.0 respectively. Between the 1995-2000 and 2001-2006 periods, the ethnic-specific crude rates decreased significantly in each ethnic group except for Pacific peoples (Table 2). Within each ethnic group, the TB rate was increased in the oldest age group; however, among those of Asian or Other ethnicity a peak age-specific rate was also present among those aged 20-29 years (Figure 3). Age-specific rates for Asian people were higher than those for Pacific peoples, other than in the 0-19 age group.

![Figure 3](image)

**Figure 3** Age- and ethnic-specific tuberculosis incidence rates in Auckland, 1995-2006

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>1995-2000 n (rate(^1))</th>
<th>2001-06 n (rate(^1))</th>
<th>Rate ratio(^2)</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>460 (65.3)</td>
<td>610 (52.6)</td>
<td>0.81</td>
<td>0.71 – 0.91</td>
</tr>
<tr>
<td>Pacific</td>
<td>256 (30.7)</td>
<td>303 (30.3)</td>
<td>0.99</td>
<td>0.84 – 1.17</td>
</tr>
<tr>
<td>Maori</td>
<td>126 (16.2)</td>
<td>78 (9.6)</td>
<td>0.59</td>
<td>0.45 – 0.79</td>
</tr>
<tr>
<td>European</td>
<td>136 (3.0)</td>
<td>77 (1.6)</td>
<td>0.55</td>
<td>0.41 – 0.72</td>
</tr>
<tr>
<td>Other</td>
<td>101 (176.0)</td>
<td>92 (93.1)</td>
<td>0.53</td>
<td>0.40 – 0.70</td>
</tr>
</tbody>
</table>

Note:  
1. Crude rate per 100,000 person-years  
2. 2001-06 rate divided by 1995-2000 rate. A rate ratio exceeding one indicates an increasing incidence; conversely, a rate ratio less than one indicates a declining incidence over the period

**Birthplace**

Information on whether cases were born outside New Zealand was known for 2200 cases, 99% of the total. Of these, 1679 (76.3%) were born outside New Zealand. The annual incidence rate among people born outside New Zealand (33.3/100,000) was significantly higher than among those born inside New Zealand (5.1/100,000). Between 1995-2000 and
2001-06 the incidence rate for those born outside New Zealand declined slightly, from 34.7 to 32.3/100,000, although this trend was not significant. However, there was a significant reduction in incidence among those born inside New Zealand (from 5.8 to 4.5/100,000; RR=0.79, 95% CI: 0.66-0.94).

Actual country of birth was known for 1560 cases born outside New Zealand: of these, the most common non-New Zealand countries of birth, each accounting for more than 5% of cases with known birthplace, were India (370, 22.0%), China (156, 9.3%), Samoa (123, 7.3%), Tonga (97, 5.8%) and Korea (93, 5.5%). After grouping countries of birth into regions, the highest incidence of TB was among people born in Asia (77.9 per 100,000), followed by people born in Other regions (52.1), Pacific Islands (40.1) and Europe excluding the United Kingdom and Ireland (11.1). Between the 1995-2000 and 2001-2006 periods, significant reductions in incidence specific to birthplace region were observed for all groups except those born in Pacific Islands countries and territories, Europe (other than the United Kingdom and Ireland), North America and Australia, although only 11 cases had been born in either of the latter two regions. Of those born outside New Zealand, 1555 (92.6%) had a recorded date of arrival in New Zealand. For these, the median interval between arrival in New Zealand and the date their TB case was reported was 3.2 years.

**Birthplace and ethnicity**

The proportions of TB cases born out of New Zealand varied markedly between ethnic groups: respectively, 98.1% and 96.9% of Asian and Other ethnicity cases were born outside New Zealand, whereas all Maori cases, 64.0% of European cases and 31.0% of Pacific cases were born in New Zealand. In all ethnic groups for whom a comparison was valid, the crude incidence rate among those born outside New Zealand exceeded that among those born in New Zealand (Table 3). The rate ratio comparing the ethnic-specific rates by those born outside New Zealand with those born within New Zealand was greatest among persons with Asian ethnicity (12.2), and lowest for those with European (2.2) or Pacific (2.7) ethnicity. The median interval between arrival in New Zealand and TB report date also varied by ethnicity: 1.1 years among those of Other ethnicity, 2.9 years among those of Asian ethnicity, 8.4 years among those of Pacific ethnicity, and 25.0 years among those of European ethnicity.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Born in NZ n (rate)</th>
<th>Born out NZ n (rate)</th>
<th>Rate ratio</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>20 (5.8)</td>
<td>1050 (71.4)</td>
<td>12.2</td>
<td>7.84 – 19.0</td>
</tr>
<tr>
<td>Pacific</td>
<td>170 (16.8)</td>
<td>378 (45.4)</td>
<td>2.7</td>
<td>2.25 – 3.24</td>
</tr>
<tr>
<td>Maori</td>
<td>202 (13.3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>European</td>
<td>130 (1.8)</td>
<td>73 (4.0)</td>
<td>2.2</td>
<td>1.67 – 2.97</td>
</tr>
<tr>
<td>Other</td>
<td>6 (22.0)</td>
<td>186 (136.9)</td>
<td>6.2</td>
<td>2.76 – 14.03</td>
</tr>
</tbody>
</table>

Note: 1 Crude rate per 100,000 person-years  
2 Ethnic-specific rate among those born outside New Zealand, divided by rate among those born in New Zealand. A rate ratio exceeding one therefore indicates that the rate among those born outside New Zealand exceeds that for those born in New Zealand
Disease site

Disease site was recorded in 99.7% of the 1995-2006 cases. Of these, 1280 (57.6%) were identified with solely pulmonary disease, 672 (30.2%) with solely extrapulmonary disease, and the remaining 270 (12.2%) with both pulmonary and extrapulmonary disease. Among the 1550 cases with pulmonary disease, 1088 (70.2%) were confirmed by laboratory testing, and the remainder were diagnosed on the basis of radiologic tests and clinical examination findings consistent with active TB. The proportion of pulmonary cases with laboratory confirmation increased significantly over the period, from 61.2% (491/802) in 1995-2000 to 79.8% (597/748) in 2001-2006, and was significantly lower among those aged less than 20 years (37.3%) than among patients aged 20 years or more (78.8%). The proportion of cases with laboratory confirmation did not alter significantly among ethnic groups. Of the laboratory-confirmed pulmonary cases, testing identified 585 (53.8%) as sputum-smear positive, with or without further confirmatory testing. A further 500 cases (46.0%) were sputum-smear negative but were culture-confirmed, and the remaining three cases (0.3%) were confirmed by PCR testing only.

Antibiotic resistance

A mycobacterial isolate was obtained from specimens collected from 1657 patients, 73.9% of the total. The most commonly-identified species was *Mycobacterium tuberculosis*, accounting for 98.9% of isolates, followed by *M. bovis* (1.1%). Of cases with *M. tuberculosis* isolates, 189 (11.6%) had an isolate with resistance to at least one first-line antituberculous agent, excluding streptomycin: 150 (9.2%) cases had isolates resistant to isoniazid; 19 (1.2%) were resistant to rifampicin; 28 (1.7%) were resistant to ethambutol; and 42 (2.6%) were resistant to pyrazinamide. The proportion of isolates with first-line resistance did not change significantly over the period (OR=1.24, 95% CI: 0.89-1.71, ns), did not vary between disease types (pulmonary vs. extrapulmonary), but was significantly more common among cases of Asian or Other ethnicity (156 cases, 16.2%) than among people of European, Maori or Pacific ethnicity (33, 5.0%; OR=3.64, 95% CI: 2.44-5.45, p<0.001). Among those of Asian or Other ethnicity, the proportion with first-level drug resistance did not vary significantly between age groups. Similarly, first-line drug resistance was significantly more common among those born outside New Zealand (174, 13.5%) than among those born within New Zealand (14, 4.4%; OR=3.42, 95% CI: 1.91-6.25, p<0.001). Fifteen patients (0.9% of the total with *M. tuberculosis* isolated) had multi-drug resistant (MDR-TB) isolates (i.e. were resistant to both isoniazid and rifampicin). Five (0.3%) MDR-TB cases were reported in 1995-2000 and 10 were reported in 2001-2006. All were born outside New Zealand.

Discussion

This analysis of TB epidemiology in Auckland shows that Auckland TB rates declined markedly in the post-war decades and reached their lowest recorded level in 1987, but have remained above this level in the succeeding two decades. The rate for the period 1995-2006 is very similar to that in 1992-93 (Calder and Priest 1996:164), the date of the most recent published review of Auckland TB data. However, over the period 1995 to 2006 the incidence rate of TB in Auckland has declined significantly, in contrast with the static trend in TB rates in New Zealand as a whole, where failure to observe reductions in TB incidence has been attributed to migration from countries with high TB incidence (Das et al. 2006b). In Auckland, declining TB rates are restricted to those born within New Zealand: in contrast, the
incidence rates for foreign-born persons have remained steady. A similar pattern has been observed in western European nations (Rieder et al. 1994:1547), the United States (McKenna et al. 1995:1072) and Canada (Enarson et al. 1989:1269).

The age distribution of TB cases in Auckland shows that the risk of developing TB is greater in older age groups, and this trend is particularly evident in the distribution of Pacific, Maori and European cases. This age distribution is typical of those in other developed countries, where progressively increasing age-specific rates occur with increasing age from late childhood (CDC 2006:18), either as a consequence of declining immunocompetence with increasing age resulting in reactivation of latent TB infection, or as a reflection of higher prevalence of TB infection in older cohorts.

Among people of Asian and Other ethnicity, however, a second pronounced peak in age-specific TB rates is shown in the 20-29 age group. In the absence of specific outbreaks affecting this group, the most likely explanation for this distribution is a secular trend in the Asian and Other population structure creating an atypical distribution of TB risk, as cases of TB among migrants from high-incidence countries are largely considered to result from reactivation of infection acquired prior to migration (Zuber et al. 1997:304). Between 1986 and 1998, New Zealand gained 162,000 nationals of countries in Asia (particularly north Asia), the largest influx of people from countries in the Asia-Pacific rim in New Zealand’s history (Bedford et al. 2000:23). The majority of permanent and long-term arrivals to New Zealand are aged under 30 years of age, reflecting New Zealand’s immigration policy, which tends to favour younger applicants (Statistics New Zealand 2002:part 5). Studies of TB among migrants in other developed countries have consistently found that the highest rates of TB among migrants occur in the first years following migration (British Thoracic and Tuberculosis Association 1975:699, Wilcke et al. 1998:219, McKenna et al. 1995:1072), although the duration of increased risk can persist for prolonged periods (Vos et al. 2004:736). High TB rates in 20-29 year old people of Asian or Other ethnicity could therefore be explained by the greater proportion of recent migrants in this age group than in others.

Disparities in TB incidence by ethnicity and birthplace remain evident, as has been identified previously in Auckland (Calder and Priest 1996:166) and in New Zealand as a whole, both recently (Das et al. 2006a, Das et al. 2006b) and during the 1980s (Stehr-Green 1992:301). Ethnic disparities in TB are likely due to two factors: the proportion within each ethnic group who have immigrated from high-incidence countries; and ethnic differentials in conditions leading to TB exposure in New Zealand. The analysis in this paper suggests that the relative contribution of these two factors differs between ethnic groups, as indicated by differences in ethnic-specific epidemiologic patterns.

Among Asian people, illness is largely confined to those born outside New Zealand and is rare in children, suggesting that the burden of disease is primarily a direct result of reactivation of infection acquired before migration. By comparison, the incidence rates for Pacific peoples did not decline between 1995 and 2006, were significantly higher among Pacific young people than among young people of Asian ethnicity, and rates among Pacific peoples born in New Zealand were one-third of those born outside New Zealand. Childhood TB is a marker for disease transmission in the community (Howie et al. 2005:1157), and recent disease outbreaks support the notion that transmission within New Zealand explains at least part of the impact of TB among Pacific peoples (Hill and Calder 2000:41, Voss et al. 2006:118). TB transmission has been associated with poverty (Weiss and Addington 1998:1011) and with household crowding (Bhatti 1995:967), and although the independent
effects of these factors have not been clearly disentangled (Lienhardt 2001:298), both are prevalent in Pacific communities and may be impacting on TB rates. The transmission dynamics among Pacific communities remain unclear: transmission to New Zealand-born people may have come from recent migrants, from those born in New Zealand or those with long-standing New Zealand residence. Moreover, transmission to New Zealand-born Pacific peoples may have occurred during travel to ancestral home countries. The introduction of systematic molecular typing to New Zealand isolates should provide a basis for more accurate estimation of scale and patterns of local transmission in the future, albeit restricted only to cases for whom isolates have been obtained.

Maori also experienced a greater rate of TB than Europeans in New Zealand, all of which occurs in those born in New Zealand. The rate of TB among Maori was similar to that of Pacific peoples born within New Zealand, but declined by 41% over the time period. This reduction may be due to the fading impact of a large outbreak that boosted case numbers, particularly among Maori, in the late 1990s (De Zoysa et al. 2001:1). However, the TB rate among Maori in 2001-06 was only 12% of that in 1983 (Taylor et al. 1986:309), suggesting that declining rates among Maori in Auckland are a long-term trend. Future analysis of TB case numbers among Maori will be required to show whether this decline is sustained.

The trend for increasing proportions of cases with microbiological confirmation is positive, as isolation of the infecting organism provides a basis for assessing the antibiotic-sensitivity profile and therefore confirmation that the prescribed antibiotic regimen is correct. Strain isolation is also an essential prerequisite for molecular typing, which can be of benefit in assisting field investigations to identify the source for a case’s infection, in understanding TB epidemiology, and in excluding false-positive case diagnoses. Younger cases tend to be less likely to have microbiologic confirmation where there is a confirmed contact with an isolate with known sensitivities (Howie et al. 2005:1160).

The prevalence of isoniazid-resistance among cases is higher in Auckland than in the United States (CDC 2006), however the percentage of Auckland cases with MDR-TB is lower than in the United States (CDC 2006) or in the European Union (Falzon and Ait-Belghiti 2007:1262). Although accurate surveillance of drug-resistance is inadequate to give an accurate picture of drug-resistant TB around the world, high levels of acquired drug resistance are considered to exist in developing countries, particularly in Asia (Raviglione et al. 1995:224). The higher level of drug resistance among cases born outside New Zealand is likely the result of factors present in countries of origin, either due to primary development of drug resistance through treatment failure or transmission of drug-resistant strains.

There are potential weaknesses in the data presented in this paper due to the reliance on notification data. For the purposes of this study it was not possible to verify that all cases notified had been accurately diagnosed. Over-ascertainment of cases, if present, would have been most likely to occur among cases diagnosed and commenced on treatment on the basis of clinical and radiologic findings only, without supplementary laboratory confirmation. 23% of cases among children in a series of cases from throughout New Zealand were diagnosed and notified inappropriately following incorrect interpretation of apparent chest X-ray abnormalities (Howie et al. 2005:1158). Over-ascertainment of cases in the current case-series seems less likely because cases in Auckland are diagnosed and notified by a limited number of highly experienced clinicians applying systematic diagnostic criteria. Furthermore, close liaison between clinical and public health staff throughout clinical management ensures
that cases for whom the diagnosis of TB is discarded following notification are removed from the notification register.

No attempt was made in this study to identify diagnosed cases who had not been notified; however, this potential source of bias is also likely to have been minimal due to the close working relationship between public health staff and the limited number of clinicians who diagnose and treat TB in the Auckland region, and due to direct reporting to public health of laboratory specimens testing positive for \textit{M. tuberculosis} complex.

Misclassification bias and mismatch between numerator and denominator may have occurred in categorisation of cases’ ethnicity. While the case report form used for notification allows for the possibility that individual cases may identify with multiple ethnic groups, a far smaller proportion of cases in this dataset had multiple ethnicities recorded than would have been expected from census data. Others have noted that disease notification data are disproportionately more frequently coded with a sole rather than a mixed ethnicity classification (Carr \textit{et al.} 2001:5). This may be partly because information on ethnicity recorded at the time of notification is often directly taken from the ethnicity information recorded in the patient’s hospital notes. Since July 1996 hospitals have been required to allow patients to identify with more than one ethnic group, however subsequent implementation of this policy has been inconsistent (Te Rōpū Rangahau Hauora a Eru Pōmare 2000). This bias may have reduced ethnic-specific case numbers (and resulting incidence rates) among ethnic groups whose members frequently have multiple ethnic identities. The alternative approach used in previous analyses of Auckland TB data assigns people with multiple ethnicities according to an arbitrarily prioritised list of ethnic groups, however this approach artificially distorts ethnic-specific rates and is discouraged by Statistics New Zealand (Statistics New Zealand 2006), so has not been employed here.

Crude rates rather than age-standardised rates were used for comparisons between ethnicities and between time periods. Given the wide variation in the age structures of the different ethnic populations, using age-standardised rates would mitigate confounding by age in calculation of relative risks. Ultimately, however, the differences in rates between the ethnic groups are so large that confounding by age would have been marginal by comparison.

This review of epidemiology of TB in Auckland during the last 12 years suggests that TB rates have declined slightly, however the experience of TB differs greatly between ethnic groups. Variation in TB epidemiology between Auckland’s ethnic communities reinforces the need to develop tailored policy and programmatic approaches to TB control.

\textbf{Acknowledgements}

The authors would like to give particular thanks to Helen Mills for diligently and tirelessly collating, recording and checking the TB notification data from which this paper draws. This paper would not have been possible without her efforts. Thanks also to the Public Health Nurses in the Infectious Diseases Control team at Auckland Regional Public Health Service for their ongoing dedication to ensuring the successful treatment of TB patients, and the thorough investigation and management of TB contacts, in the Auckland region.
References


Chapter 2
Man’s Best Friend: Implications of Tuberculosis in a 16th Century Neutral Iroquois Dog from Canada

Jodi Lynn Barta

Archaeological evidence is not the first source of data that one would consider informative when it comes to investigating tuberculosis in modern populations. However, technological advances have made possible the analysis of DNA from ancient skeletal remains, thus providing an opportunity to travel through time at a molecular level. In this case, a young dog that lived in a Canadian First Nations community long ago provides a glimpse into parallel conditions that exist between the epidemiological factors operating in a 16th century community and those that are present in modern populations who continue to struggle with the burden of tuberculosis.

This paper is a thought extension of an ancient DNA (aDNA) study that was conducted on the skeletal remains of a 16th century dog excavated from the Cleveland site (AhHb-7), a Neutral Iroquois village in southern Ontario, Canada (Bathurst and Barta 2004:917-925). Ancient DNA analysis showed that the dog had tuberculosis and, as a result, suffered from hypertrophic osteoarthropathy (HOA), which is visible as lesions on the skeleton (Bathurst and Barta 2004:917-925; Figure 1). In their study, the authors postulate that because tuberculosis is anthropozoonotic (spread between humans and animals), dogs may have acted as reservoirs of tuberculosis in this community (Bathurst and Barta 2004:924). Therefore, it is pertinent to question whether dogs may continue to play a role in the maintenance and transmission of tuberculosis in communities today.
The following touches on the current state of tuberculosis in the world, and some of the parallels that are present between the 16th century community where the archaeological dog resided and those where modern dogs are part of social groups today. It addresses the possibility of dogs acting as a reservoir of tuberculosis infection in modern populations by examining current evidence on the susceptibility of dogs to infection, case studies involving anthropozoonotic transmission of infection, and factors contributing to the maintenance of this reservoir despite concentrated efforts by public health workers to control the spread of tuberculosis. This examination also emphasises the importance of the push for collaborative efforts between public health professionals and veterinarians as they continue to confront zoonotic diseases including tuberculosis.

Despite the advent of effective chemotherapy, tuberculosis is still a major problem in many populations today (Davies 2003:235-236). One of the problems that occurred in developed nations that saw a major reduction in incidence following effective tuberculosis campaigns is the ensuing complacency and comfort of policy makers feeling that the battle was won and the disease is no longer an issue (Raviglione 2003:5). In other words, tuberculosis became predominantly a disease of the poor and destitute, and as such considered a social rather than a medical issue (Davies 2003:241). However, tuberculosis is again on the rise globally and sound medical management and understanding of the risk factors is essential to providing necessary treatment and control of the disease. This is especially critical when considering the burden of HIV infection (Davies 2003:238), increased poverty in urban settings, recent waves of migration from tuberculosis high-burden countries (Raviglione 2003:5), and the development of multi-drug resistant strains of *Mycobacterium tuberculosis* (MDT-tuberculosis) (Shah *et al.* 2007:380). Thus, it is especially important to focus attention on at-risk groups in order to minimize the devastating impact of tuberculosis for all.

Examining the similarities between the social and behavioural characteristics of members of the 16th century Aboriginal community studied and those in at-risk modern communities highlights the connections that make this comparison meaningful. Of interest are the prime
factors that provided opportunities for transmission of tuberculosis in the 16th century Iroquoian population. These include crowded, poorly ventilated living conditions that were conducive to the accumulation of refuse and unhygienic conditions (Saunders et al. 1992:117-125), and the high degree of attachment evident in the relationship between the people and their dogs (Thwaites 1896:1910). This attachment led humans to treat them as they would children, sharing beds, plates and food with them (Thwaites 1896:1910). This is especially pertinent when dealing with sick animals. The dog with HOA would have had great difficulty moving around due to its condition and would have required constant care (Bathurst and Barta 2004:917-925). This close relationship in crowded living quarters with infected animals may have provided the conditions for transmission and maintenance of the disease within and between the dog and human populations.

Similar to the 16th century Iroquoian village population, modern communities face some of the same factors that contribute to the transmission of tuberculosis including over-crowded, poorly-ventilated living arrangements and unhygienic conditions. In particular, increasing numbers of people are living in poverty, where poor nutrition, compromised immune systems and limited access to healthcare are all contributors to the spread of tuberculosis (Davies 2003:235-242, Hwang 2001:230-232). People also continue to have close relationships with their dogs regardless of their social conditions, including homelessness (Kidd and Kidd 1994:715-722, Taylor et al. 2004:353-368). This attachment is not dependent on the ability to provide adequate food and veterinary care for the animals (Kidd and Kidd 1994:720-721). This level of attachment between humans and their dogs have led some to suggest that indeed humans and dogs are co-domesticated (Groves 1999:1-12), and it is unlikely that this relationship will change in the near future. Thus, it is the similarities between modern conditions and those in the past that help to warrant further investigation into the possibility of dogs as reservoirs of tuberculosis infection.

The first question to address is the ease of transmission of tuberculosis between dogs, as well as from dogs to humans or humans to dogs. A comprehensive study by Bonovska and colleagues (2005:165-170) showed that dogs are susceptible to \textit{M. tuberculosis} infection by oral, subcutaneous, intraperitoneal and intravenous means, and that control dogs that were not experimentally infected became infected through exposure to the dogs that were infected, regardless of whether or not those animals showed clinical symptoms of disease. The authors suggest that the infection can run subclinically in dogs who are carriers, excreting mycobacteria and infecting others in close contact while maintaining a healthy physical appearance (Bonovska \textit{et al.} 2005:169). This presents difficulties when trying to detect tuberculosis in living dogs and subsequently makes it very difficult to determine the extent to which dogs might act as reservoirs and the potential risk for humans and other animals (Bonovska \textit{et al.} 2005:169). Also unclear is the aetiology of the disease in dogs, thus making it difficult to determine if an animal may be infective for long periods before manifesting disease symptoms. This is illustrated by a case from Brazil in which 14 of 18 members of one family had positive Mantoux tests, five of whom showed clinical symptoms of the disease (Megid \textit{et al.} 1994:309). Closer examination revealed that the family dog had an active tuberculosis infection of unknown duration but displayed no clinical symptoms (Megid \textit{et al.} 1994:309). The authors point out that the friendly behaviour of pets favours constant and intimate contact. However, family animals are rarely considered when tuberculosis patients seek health care services, which leaves them as wells of new infection (Megid \textit{et al.} 1994:309). This speaks to the assumption that 90% of all tuberculosis cases in industrial countries are endogenous reactivation of previously acquired infection (CDC 1990:9-12)
when, in reality, recently transmitted cases of tuberculosis, including exogenous reinfections, are much more frequent than previously realized (Seidler et al. 2004:96-102). Despite evidence to the contrary (Bonovska et al. 2005:165-170), there is an underlying belief that dogs are by some mechanism resistant to tuberculosis (Huard et al. 2006:4284). It is unclear whether this might reflect the lack of veterinary care for the dogs that are in situations where they may contract tuberculosis, the subclinical nature of some canine cases of the disease, or even the presence of generalized clinical symptoms misdiagnosed due to unfamiliarity with the disease. While clinical signs of tuberculosis infection are often chronic in dogs and can be associated with the respiratory tract, they may vary depending on the dissemination of the organism (Hackendahl et al. 2004:1575-1576). These include lethargy, poor appetite, vomiting, diarrhoea and weight loss (Clercx et al. 1992:207-208, Turinelli et al. 2004:177-179). Even antemortem diagnosis may be difficult and require both histopathologic and bacteriologic examinations (Hackendahl et al. 2004:1576), though the development of new diagnostic assays is promising (Aranaz et al. 1996:276-280, Bonovska et al. 2005:165-170). This raises questions about the costs of veterinary care, and how often a dog is ill or dies in a crowded inner-city neighbourhood, homeless shelter, or while living on the street with its owner, where there is no investigation into the cause of death. Certainly, veterinary care is not as accessible for those living in poverty and presents problems for dog owners who, despite being extremely attached to their pets, cannot provide adequate food, shelter or healthcare for their animals (Kidd and Kidd 1994:715-722). This is in and of itself important because these are the very same individuals that are most at risk for contracting tuberculosis themselves (Davies 2003:238-242, Huang 2001:231)

A number of studies in the recent literature refer to dogs and pathological cases of *M. tuberculosis* (Aranaz et al. 1996:276-280, Bauer et al. 2004:168-172, Clercx et al. 1992:207-211, Erwin et al. 2004:2258-2260, Megid et al. 1994:309-310, Hackendahl et al. 2004:1573-1577, Pavlik et al. 2005:296, Saxegaard and Svenkerud 1982:309-311, Turinelli et al. 2004:177-181) or *M. bovis* (Ellis et al. 2006:46-48, Gay et al. 2000:78-81, Mota et al. 2001:410-412). However, few mention the status of the humans or other animals that had close contact with the infected dog. One particular case study involves the diagnosis of *M. tuberculosis* infection in a five-year-old dog that had a three-year history of recurrent disease (Clercx et al. 1992:207-211). In another case, a four-year-old dog with a history of poor health was diagnosed with *M. tuberculosis* infection (Turinelli et al. 2004:177-181). Yet another case focuses on the similarities between the cytological findings in a three-year-old dog with an eight-month history of productive cough and those that are common in human patients (Bauer et al. 2004:168-172). Each of these studies involves advanced cases of tuberculosis with long-term illness of the animal and little information about the impact of that illness on contact populations.

In contrast, a recent report detailed the same strain genotyping of an elderly tuberculosis patient and her dog (Erwin et al. 2004:2258-2260). This patient had no apparent tuberculosis exposure and responded well to treatment. Six months later her dog, which had been her constant companion for three years, was diagnosed with tuberculosis after suffering from cough, weight loss, and vomiting for several months (Erwin et al. 2004:2259). Genotyping of the *M. tuberculosis* isolates from the dog and the owner revealed that the cases were indistinguishable (Erwin et al. 2004:2259). Erwin and colleagues (2004:2259) suggest that the human owner was the primary source of the tuberculosis infection because she was diagnosed first and that, historically, evidence of transmission has been reported as being from humans to pets (Hawthorne and Lauder 1962:858-869, Liu et al. 1980:164-167).
However, as they point out, there are also cases where \textit{M. tuberculosis} and \textit{M. bovis} infections in dogs and cats have been transmitted to humans (Snider 1971:877-887). Given the uncertain aetiology of tuberculosis in dogs and the close timing of symptom onset, the direction of transmission is not clear but this study does highlight the importance of monitoring companion animals. It also draws attention to the elderly whose standard of living can decline with advancing age leading to poorer nutrition and compromised immune systems (Davies 2003:238). However, like the homeless, the elderly are often very attached to their companion animals, and can benefit from pet ownership through maintained or enhanced physical health (Raina \textit{et al.} 1999:323-329). Thus, all identified cases of tuberculosis in the elderly should include screening of their dogs along with other close personal contacts.

One of the greatest problems with tuberculosis is case detection among infectious cases. Despite the World Health Organization target of 70% case detection by 2005, only five of the 22 highest burden countries had met or exceeded 50% detection by 2000 (Raviglione 2003:10). While none of these high-burden countries is located in Europe, North America or the South Pacific, they include the most populous countries of Asia, including India, China, Indonesia, Bangladesh, and Pakistan, which account for over half of the global tuberculosis burden (Davies 2003:235). This is significant when considering that within the developed world the greatest factor contributing to the increase in the number of cases is migration (Davies 2003:239). As Davies (2003:240) points out, the tuberculosis that 200 years ago in western Europe killed one in four people and was exported through trade and empire-building throughout the world is now being reimported with those migrating for economic or political reasons. The impact of reimportation into industrialised countries with a low tuberculosis incidence rate has been demonstrated in Denmark, Iceland, Luxembourg, the Netherlands, Norway, Sweden, Switzerland, the United States, Canada, Australia, and the UK (Eurotuberculosis 2002, Borgdorff \textit{et al.} 2000:287-294, McKenna \textit{et al.} 1995:1071-1076, Rose \textit{et al.} 1998:173-179, Watkins \textit{et al.} 2002:641-644). There is even a case report where a dog moved from a high incidence area (West Africa) to a low incidence one (France) bringing \textit{M. tuberculosis} infection along (Turinelli \textit{et al.} 2004:177-181). Therefore, case detection in both developing and developed countries is critical because early detection and treatment of infectious cases is necessary to decrease the risk of transmission and keep the tuberculosis caseload low. Awareness of possible reservoirs of infection, such as pet dogs, may help to reduce the possibility of the spread of new infection or exogenous reinfecion in individuals most at risk for contracting tuberculosis.

The importance of zoonoses in public health is receiving considerable recognition as global health programmes struggle to deal with tracking and control of emerging infectious diseases such as avian influenza virus, West Nile virus, and resurgent bovine tuberculosis (Kahn 2006:556-561, Pal 2005:586-591). The continuing problem of tuberculosis in animals of economic interest is emphasised and closely monitored as a source of disease in both humans and cattle (Amanfu 2006:330-335, Baker \textit{et al.} 2006:1068-1073, Corner 2006:303-312, de la Rua-Domenech 2006:77-109, Ocepek \textit{et al.} 2005:3555-3556). Recognition of the problem has led to a call for greater collaboration between public health workers and veterinarians as a means to help reduce the prevalence and incidence of zoonoses (Coulibaly and Yameogo 2000:53-57, Kahn 2006:560-561, Pal 2005:590). This is critical in the case of tuberculosis since \textit{M. tuberculosis} and \textit{M. bovis} can both be passed between humans and livestock (Amanfu 2006:331-332, de la Rua-Domenech 2006:86-87, Ocepek \textit{et al.} 2005:3555-3556). Dogs are an important part of the triad because they can be exposed to mycobacterial infection from wildlife, livestock and human sources, and may act as a maintenance or "spill-
over” host (Morris et al 1994:172). While most spill-over hosts are considered a dead end, it is now recognized that some spill-over hosts, such as dogs, are also “amplifier” hosts, acting as incidental sources of tuberculosis for livestock or other species (de la Rua-Domenech 2006:86, see de Lisle et al. 2001:86-111). Thus, dogs that live in areas known to have high infection rates in wildlife or farm animals should be treated as potential amplifier hosts and cannot be discounted as a source of direct or indirect transmission of mycobacterial infections (de la Rua-Domenech 2006:86, Gay et al 2000:80).

Zoonotic diseases are a public health problem throughout the world, especially in regions where inadequate infrastructure and financial resources restrict their control (Coulibaly and Yameogo 2000:53). Kahn (2006:556-561) outlines three areas where collaboration between veterinarians, physicians and public health professionals would help in the control, prevention and understanding of zoonoses: at the individual health level, in population health and also in comparative medicine research. At present, the lack of coordination between the organisational structures and professionals limits each of their abilities to reduce the prevalence and incidence of zoonoses with complex epidemiology (Pal 2005:589). There is little doubt that collaborative research projects conducted by physicians and veterinarians would be of great benefit to the understanding of host interactions and the transmission of disease causing species of the *Mycobacterium tuberculosis* complex.

In summary, although the risk in the general populace of contracting tuberculosis from a dog in a developed country is considered to be low, there are a number of factors suggesting that their potential as amplifier hosts should be recognised and addressed. These include the evidence that suggests that dogs are susceptible to infection and can harbour that infection without any outward clinical signs for an unknown length of time, and that symptoms when they do arise may be generalised, and therefore not recognised as possible cases of tuberculosis. Also important is the increase in immigration to low incidence regions from high burden countries with low case detection rates. This highlights the importance of increased surveillance in both developing and developed countries. Increasing levels of poverty in urban centres, HIV status, substance abuse, declining standards of living in the elderly, and homelessness all contribute to rising tuberculosis rates and it should be recognised that those most likely to contract the disease are also those that face difficulties when accessing healthcare for themselves and their pets. Therefore, while the general populace may be at low risk, there are specific subsections of the population where dogs as amplifier hosts can act to transmit new cases and promote exogenous reinfection of previously treated patients. This can be especially problematic for immunocompromised individuals and stresses the need for collaboration between physicians and veterinarians in comparative medicine. Because animal ownership has both psychological and physiological benefits, it is necessary to find a balance between those benefits and the health of the people and dogs that are their companions.

In the end, thinking about one little dog in Canada that lived and died with tuberculosis so long ago has led to a realisation that the past and the present are not all that far apart. Just as the dog inspired thoughts about conditions conducive to the maintenance and spread of tuberculosis within the 16th century Iroquois village, it also highlights evidence that suggests that dogs may continue to be a reservoir in at-risk populations today. Using the past as an example, it is hoped that continued research and diligent verification of the health of dogs living in close contact with individuals or in communities with active tuberculosis cases will contribute to the reduction of new tuberculosis infections in the future.
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References


Chapter 3
The Political Ecology of Tuberculosis in Auckland: An Interdisciplinary Focus
Judith Littleton and Ron King

One of the acknowledged ‘truths’ about infectious disease and the social sciences is the need for an interdisciplinary perspective to tackle issues of public health. While it would be difficult to find a social scientist who would disagree with this statement, it is rather more difficult to achieve interdisciplinarity in research (e.g. Borofsky 2002, Turshen 1984), and to point to its specific influence on research outcomes. As Turshen (1984:17) wrote, “the division of knowledge into disciplines handicaps problem solving in public health.” This paper addresses the issue of interdisciplinarity from the focus of Auckland. Specifically we describe the organisation of one interdisciplinary project, the ‘Political Ecology of TB in Auckland’ (fondly known as the PE of TB), and ask the question does interdisciplinarity provide new perspectives on the issue?

Conceiving a research project

The PE of TB project was a four year project funded by the New Zealand Health Research Council and the University of Auckland. The project commenced in 2002; funding finished in 2006. It involved academics from a range of disciplines: anthropology (both biological and social), geography, history and initially sociology, as well as students from these areas and political studies. The students undertook the main work as a series of Masters and Doctoral theses.

The conception of the project began with interdisciplinarity within anthropology. Julie Park and I co-teach an undergraduate course in medical anthropology. One of the main themes of the course is that the way to understand health is through multiple approaches. From that we became involved in the Social Science for Public Health programme at the University. This meant there were numerous places where there was a forced engagement between different social science perspectives around the issue of health. Arguing for interdisciplinary approaches while teaching raised the prospect of actually engaging in interdisciplinary research. Hence the research impetus for a social science study was born. But of what?

The other side of the coin in the project became public health and specifically TB. In informal discussions, Dr Lester Calder, then Medical Officer of Health in Auckland, shared his concern that the rates of tuberculosis appeared to be showing an upward trend. In particular, he was worried about the difficulties of contact tracing, ensuring timely diagnosis, and patients adhering to treatment (Calder 2000, Calder et al. 2001).

TB in Auckland

TB remains a major cause of death around the world despite the condition being largely treatable (Gandy and Zumla 2002). While TB is commonly assumed to be associated with poverty and third world populations, as in many other places it never really disappeared from New Zealand. The increase in numbers observed around 2001 was caused by this mixture of local and global history.
The epidemiology of tuberculosis in New Zealand has been discussed in Chapter one by Thornley and Pikholz. The most obvious gradient is the disparity in rates by ethnicity (Table 1). This is particularly salient for Auckland which experiences the highest TB rates with a very high proportion of overseas born patients (Figure 1).

Table 1   Tuberculosis Disease (TBD) rates in New Zealand from 2000-2004 by selected region of birth (derived from Das et al. 2006b:Table 2).

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<thead>
<tr>
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<tbody>
<tr>
<td>New Zealand</td>
<td>562</td>
<td>2890869</td>
<td>3.9</td>
</tr>
<tr>
<td>Australia</td>
<td>3</td>
<td>56259</td>
<td>1.1</td>
</tr>
<tr>
<td>Europe (high incidence)</td>
<td>9</td>
<td>15939</td>
<td>11.3</td>
</tr>
<tr>
<td>Europe (low incidence)</td>
<td>33</td>
<td>268731</td>
<td>2.5</td>
</tr>
<tr>
<td>North America</td>
<td>3</td>
<td>21279</td>
<td>2.8</td>
</tr>
<tr>
<td>South and Central America</td>
<td>5</td>
<td>3519</td>
<td>28.4</td>
</tr>
<tr>
<td>Africa</td>
<td>151</td>
<td>38106</td>
<td>79.3</td>
</tr>
<tr>
<td>Asia</td>
<td>707</td>
<td>165777</td>
<td>85.3</td>
</tr>
<tr>
<td>Pacific Islands</td>
<td>249</td>
<td>117987</td>
<td>42.2</td>
</tr>
<tr>
<td>Birth country unknown</td>
<td>176</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall Total</td>
<td>1898</td>
<td>3737277</td>
<td>10.2</td>
</tr>
</tbody>
</table>

There are, however, other gradients. Rates of TB increase with increasing social deprivation, measured by the NZ Deprivation Index (10 being the most deprived, one the least). Unsurprisingly then, there are large disparities based on geography, not just on a national scale, but also across Auckland (Figure 2). But there are other gradients associated with TB:
social networks (particularly for outbreaks) (De Zoysa et al. 2001), and life courses (particularly people’s prior history of TB) are two of the many.

**Figure 2** TB Notifications in Auckland 1994-2004 (indicated by height of the block) compared to the NZ Deprivation index (1= least deprived [dark brown], 10= most deprived [dark green]).

The ethnic distribution of TB is statistically the most obvious of these gradients but ethnicity interacts with each of these others in complex ways. For instance, for living Pakeha (European New Zealanders) and Maori, the main experience with TB was in the 1940s-1960s, and these groups carry that legacy among the elderly, giving them a distinctly different age profile to populations from Asia where the main risk of TB is among young people migrating into difficult living circumstances (Das et al. 2006a). The research therefore needed to be designed to pay attention to these particular gradients which involve macro-level factors such as global patterns of migration, transnationalism, and the political economy of New Zealand.

**Using a political ecology framework**

A theoretical model which explicitly explores this link between individuals and macro-level factors is political ecology (Bryant and Blakely 1997, Leatherman 2005). In using political ecology we are focussing on the production of inequality within an ecological setting, what Leatherman (2005) calls a “space of vulnerability”. While political ecology often espouses the micro in the macro or vice versa, many of the studies have been very large scale, focussed on third world environments or natural environmental issues and have had a tendency to discount individual agency (Dressler 2001, Leslie and Little 2003). We are concerned to add an interpretative approach to analyse individual experiences and understandings and the processes of their interaction with larger scale forces, such as prevailing economic structures, political context and migration patterns. Our aim is to discover:
how people variously experience sickness, how indigenous classifications of disease are
shaped by changing environments, how medical resources are differently interpreted and
accessed by local populations and how people interpret the relationship between their

Yet the starting point for this investigation is the experiences of individuals with tuberculosis.
Using this framework we were concerned to address the following specific questions:

1. What factors facilitate early presentation to doctors by TB patients (timely diagnosis)?
2. What factors facilitate or create barriers to adherence to treatment?
3. What are the dynamics of interactions between patients and health professionals?
4. What can we discover about transmission of and susceptibility to TB in terms of socio-
cultural, economic and spatial concomitants?
5. What is the historical context of TB in New Zealand and the Pacific from the Second
World War period to the present?

The research started with those already diagnosed with tuberculosis rather than at the broader
level. There are a number of reasons for this, both pragmatic and intellectual. First, the initial
concern stated by Lester Calder was focussed on those with tuberculosis – their diagnosis and
their adherence to treatment regimes. Second, in New Zealand today TB is largely invisible
and unknown; the people for whom TB is salient are those who have been diagnosed with it.
This is a difficulty with the research – we are talking to those for whom the process of
diagnosis and treatment has been largely successful. We have to extrapolate from their
experiences, the experiences of their acquaintances and of community members how
diagnosis and treatment might fail. The intellectual reason, however, is (going back to Harper
2002) that from a political ecology perspective the individual matters. A crucial focus of such
work needs to be the role of human agents in responding to “conditions of vulnerability, such
as poverty and illness, and thus dialectically creating, in part the conditions of their own
vulnerability” (Leatherman 2005:67). It is only from the individual experience that we can
discern which macro-level factors do matter in direct and indirect ways in the transmission,
discovery and treatment of tuberculosis.

Making that work with multiple disciplines

The marked ethnic gradient in tuberculosis meant that any research needed to work with
multiple ethnicities. One way of tackling this was for the project to comprise several
community studies. Since a political ecology approach recognises the salience of history, an
historical analysis was also built into the project. These different studies were each developed
by a student as part of either Masters or Doctoral research. The four Masters projects have
been: a study of Pakeha with tuberculosis (Searle 2004), one with Maori (Oh 2006) one with
Pacific people (Ng Shui 2006), and one examining the history of TB among Maori (Finn
2006). The three Doctoral projects have been: one with a refugee community (Lawrence,
Chapter 17), one with Asian people (Anderson, Chapter 16), and one dealing with the history
of TB in New Zealand post 1945 (Dunsford, Chapter 14).

Strictly speaking, not each ‘community’ study represents a community. Pakeha as the most
populous group in Auckland, as well as the socially dominant, do not really constitute a
community. The ‘Asian’ study actually encompasses three separate ethnicities not one single
community. However, as Anderson’s chapter points out, the delineation of ‘Asian’ rather than specific ethnicities was preferred by the participants in her study. Relevant advisors from the communities were appointed onto the advisory board for the project along with representatives from Auckland Regional Public Health.

In 2002 a diagram was made to demonstrate how the project was formulated (Figure 3). At the time we did not realise how crucial history (shown in the diagram as the underlay) would be to the entire project. We have increasingly relied on the historical studies to provide us with the underlying historical political economy. At the level of specific communities we have examined the ecological relationships and individual interpretations of tuberculosis.

![Figure 3: Schema of the project indicating the individual community projects and the underlying historical component.](image)

One further part of the project has been spatial analysis looking at the intersection of TB cases with the provision of services, the distribution of resources and the geographical distribution of people in Auckland.

There are two crucial points to this sort of project organization. First, while there was an overarching set of research questions and a project framework, each piece of research has been undertaken as an independent study and the focus of analysis reflects the theoretical engagement of the researcher. Thus, while there is a common data set, Oh’s political studies thesis on TB among Maori (Oh 2006) explicitly explores the status of the Treaty of Waitangi while Searle’s social anthropology thesis on TB among Pakeha is focused on the issue of
stigma and care (Searle 2004). We were concerned to make sure we have similar sets of data from each study (i.e., interviews with patients, interviews with community members, etc.) but each individual has added their own distinct focus to those data. Second, while this diversity could have led to a distance between the individual studies, this distance was fought against in a very explicit fashion. From the beginning the research was seen as a social engagement and an engagement for the purpose of training. That means there have been monthly meetings of those involved but even more significantly a regular reading and writing group where we have come together to discuss papers relevant to the research or to review each other’s work. For those of us not undertaking or directly supervising the individual studies this has allowed us all to keep track of the findings of each separate part of research.

An interdisciplinary finding = local ecologies

This research model approaches Borofsky’s conception of interdisciplinary research: rather than focussed on disciplinary boundaries and crossing them the focus should lie in “substance and styles of how anthropologists engage with public problems” (Borofsky 2002:474). So far, the PE of TB has been focussed on a public problem which has been attacked by multiple workers in a similar style. Have we come to any overall findings that reflect the project’s interdisciplinarity?

As many of the chapters in this volume reflect, one of those overarching findings has been the importance of stigma; another has been the importance of marginalisation. What has surprised us is however, the link between the epidemiology of tuberculosis, treatment and the experience of individual communities. After all, we are focussed upon one pathological condition, TB, in one urban area, Auckland, comprising one health care system. Yet for each group, TB is transmitted, detected and experienced in a particular fashion which reflects history at multiple levels: the life history of individuals, the history of particular communities and the history of New Zealand itself. We have termed this phenomenon ‘local ecologies’. Lock (1993, Lock and Kaufert 2001) coined the term ‘local biologies’ to highlight how cultural beliefs influence the construction, experience, and interpretation of biological process [and] biological difference…moulds and contains the subjective experience of individuals and creation of cultural interpretations… [A]natomical changes are not simply the result of a slow adaptation of the biological organism to the environment but are also the products of human imagination and activity (Lock 1993: 39).

In thinking of local ecologies we are also acknowledging the localised nature of culturally loaded expectations, knowledge and experiences but emphasising that this goes beyond the level of individual biological experience to encompass the ecological webs of host, pathogen, and environment. The following demonstrates what is meant by local ecologies in the context of four of the communities involved in the project.

Pakeha

The most straightforward way of envisioning these local ecologies is through the use of Geographic Information Systems (GIS). Figure 4 displays the distribution of Pakeha across Auckland: the higher the block the higher the percentage of Pakeha in the local population. Above this is overlain (as if a miasmic cloud) the distribution of TBD cases between 1995-
Over this period the rate of TBD among Pakeha was around 3 per 100 000 (Das et al. 2006a) so in reality there are only very small gradients involved in this particular distribution.

The comparison of these two spatial distributions however demonstrates that there is no obvious clustering of TBD to particular geographical areas. Among Pakeha TBD is primarily an individual and isolated phenomenon. Epidemiologically this is also the case. Most TBD among Pakeha occurs in older individuals, and of the nine Pakeha participants in the project most had had either an earlier experience of TBD or association with people with TB during the 1950s and 1960s (Searle 2004; and Chapter 15). Current TBD among these patients represents primarily reactivation of long standing infection, a residue of New Zealand’s history of tuberculosis, and this is a common epidemiological pattern in many industrialised countries (Searle 2004).

This pattern of isolation and a long period of time between infection and activation, however, also played out in patients’ experience of diagnosis and treatment. Most of the Pakeha involved in the project had experienced delays in diagnosis. The delays were the result of multiple factors including comorbidities among the elderly but one factor was a lack of recognition by general practitioners of the possibility of tuberculosis among Pakeha. The low prevalence of tuberculosis in New Zealand after the 1960s and current reports which tended to link tuberculosis exclusively with non-New Zealand born peoples (Park and Littleton, Chapter 5) contributed to a lack of awareness of it particularly among Pakeha. As one participant said in relation to their diagnosis:

… 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. (David cited in Searle 2004:94).
Isolation during their treatment also characterised many of the patients interviewed by Searle. The majority lived alone and some managed the whole issue of tuberculosis by further isolating themselves and restricting information flows to other people. In this situation the Public Health Nurses then became a crucial link and relationship during the treatment phase (Searle et al. 2006, Searle chapter in this volume). While many coped with the stigma of tuberculosis through a range of strategies, those already marginalised were further isolated by the diagnosis. The geographic pattern of isolation carried through, therefore, the multiple layers of infection, diagnosis and treatment.

Maori

TB among Maori is even more dispersed reflecting the greater geographic spread of the population (Figure 5). The distribution of TB cases does indicate some clusters but, as work by de Zoysa et al. (2001) has revealed, clusters of TB among Maori can involve long-distance linkages. One long-running outbreak has involved people over the length of the North Island, reflecting the long-distance kinship and social networks of Maori as well as the greater mobility of segments of this population. Interviews, however, with patients with TBD revealed that the diagnosis of TB itself could contribute to this mobility as households became fractured or people moved following diagnosis (Oh 2006:63-64).

![Figure 5](image.jpg)

**Figure 5** Distribution of TB notifications 1994-2005 among Maori (represented by pink contours) overlaying a 3D distribution of Maori in the Auckland area (based on 2001 census data).

In terms of treatment this mobility created very real issues for Maori with TBD. Many participants were located at great distances from the major clinics (Auckland Hospital, Green Lane, Middlemore) and in areas not well served by public transportation. Less than half of
the people interviewed had access to their own car and were reliant upon relatives, public health nurses, or taxi chits provided by the ancillary organisations (Oh 2006:68). This reliance was compounded by the contraction of social networks of some once diagnosed with TB. In contrast to Pakeha where the dominant picture of TB is one of isolation, for Maori one of the dominant issues was dispersal and mobility.

Asi

While there has been Asian migration into New Zealand from very early colonial settlement, many Asian communities tend to be of a much more recent date reflecting increases in migration during the 1980s and 1990s (Bedford and Lidgard 1996). Consequently in Auckland (in contrast to Maori and Pakeha) particular communities are clustered into distinct locations (Figure 6). Consistent with other immigrant populations from high incidence countries (Das et al. 2006b), many of these communities experience high rates of TB. However these cases are localized and map onto the areas of high population density for the communities. Transmission is often similarly narrowed. For example, in 2005 only 31% of all TBD cases where these data were recorded had contact with a known case (Population and Environmental Health Group 2006).

Figure 6  Distribution of TB notifications 1994-2005 among Asians (represented by pink contours) overlaying a 3D distribution of Asians in the Auckland area (based on 2001 census data).

The coincidence between population numbers and TBD shows how there is a prospect for community engagement around de-stigmatising the disease and promoting effective diagnosis and contact tracing. Miller’s paper in this volume is an analysis of one such programme, while Anderson’s discussion of stigma shows why such programmes are particularly necessary for a group that is already marginalised in terms of wider society.
Pacific peoples

In contrast, Pacific populations have been established in Auckland since the 1960s and many people identifying with some form of Pacific Island ethnicity in Auckland are locally born. This longer term community history is reflected in the lack of a direct match one-to-one between clusters of TBD and areas of highest population density (in contrast to more recent populations, Figure 7). Rather the distribution of TBD reflects a mixture of individual cases (tending to occur in high population number areas) and some major outbreaks which may not occur directly over the areas of highest population numbers (Voss et al. 2006).

Figure 7  Distribution of TB notifications 1994-2005 among Pacific people (represented by pink countours) overlaying a 3D distribution of Pacific people in the Auckland area (based on 2001 census data).

Pacific populations in Auckland experience a double problem: some of the highest rates of TB by ethnicity and age are among elderly Pacific people (Population and Environmental Health Group 2005) but the rates are increasing among the young (Voss et al. 2006). Pacific people in Auckland experience the effects of history (particularly high rates of TB in some of the islands) as well as their current economic position (lower incomes, higher rates of unemployment) in a transnational population. In this respect, while the project has dealt with Pacific populations as a whole (Ng Shui 2006), it has become clear during the project that the experiences of people from different island groups are quite different. For some populations TBD occurs among those living in Auckland but has not been reported in their home country for a long time. For others high rates of TBD occur in the place of origin (but not necessarily birth) of those affected. This makes for a complex ecology involving not merely the geographic confines of Auckland but of the broader Pacific.

So what do we have and how is that different?

These particular patterns make for specific public health issues with different groups as well as reflecting the different experiences of TB and risks of TB. It is at this level that the local ecologies start to clearly appear. It has also become apparent that in relation to some of these patterns other major infectious diseases (e.g., meningococcal disease) could easily be transported into the picture and show a very similar pattern in different communities. Often the underlay of infectious disease has been seen as one of inequality summed up in measures
of household crowding or income inequality. TB, however, forces the attention on how inequality can exist in multiple ways beyond the economic such as in the effects of historical inequality (coming through now in the disparate rates among elderly), social marginalisation (evident in the experiences of Asian people with TBD), and the current transnational linkages which create persistent inequalities (apparent in the complex pattern of TB among Pacific populations). The study points out that Leatherman’s (2005) ‘space of vulnerability’ is not the same space for different communities even within the one city. It is up to us in further work to tease out these underlying vulnerabilities and effective ways to tackle them beyond the simple focus upon particular ethnicities.

References


The term ‘syndemic’ refers to linked health problems where two or more afflictions can be observed to be acting synergistically and contributing to an excess burden of disease in a chosen geographical area and population (Centers for Disease Control and Prevention 2005:1). A syndemic orientation explores the connections between biological afflictions and the social conditions that create and sustain them (Figure 1). According to syndemics theory, if a disease is eradicated without taking measures to correct the social conditions that enabled it to thrive, this disease, or a similar one, will return because the social conditions that create the opportunity for disease to flourish still remain. In other words, the biological and social conditions that act synergistically to create an excess burden of disease must be addressed simultaneously.

The idea of a syndemic theoretical framework to examine disease has existed in the social sciences for almost two decades. Rodrick and Deborah Wallace have discussed the effect of a “planned shrinkage” policy in New York City from the late 1970s to the 1980s, during which time violent death, substance abuse, and AIDS rates rose dramatically in the Bronx, which contained a large population of impoverished African-American and Hispanic individuals (Wallace 1990:802). This syndemic of “contagious urban decay” (Wallace 1990:802) began with the withdrawal of essential municipal, state, and federal services relating to employment, fire protection, tuberculosis screening, and housing, among other government-funded programs as a response to the 1975 fiscal crisis facing New York City (Wallace 1990:802, Freudenberg et al 2006:424-426). For example, the Department of Health suffered a budget cut of 20% between 1974 and 1977, and closed 6 of 14 chest health clinics responsible for screening and diagnosing individuals for tuberculosis, while “the police department lost 20% of its workforce, eliminated the youth unit and the organized crime squad, and cut the narcotics squad by 33%”, all during the same time period in which heroin and other illegal drug use increased dramatically (Freudenberg et al 2006:425,427).

Following these and other withdrawals of government services and the destruction of low-income housing, by the city and as a result of arson, the outcome was essentially a forced
mass migration of nearly one quarter of the city’s population to other areas (Wallace 1990:802, Freudenberg et al 2006:426). By 1982, federal support for low-income housing had stagnated, and the number of poor people in the city had increased by 20% from 1970 to 1980, despite a population decrease of 10%. In 1975, state welfare grants dropped on average 50% (Freudenberg et al 2006:426). In addition, as employment opportunities and government assistance programs sharply decreased, poverty rates increased, as did violent deaths, suicides, and biological pathology rates, including AIDS (particularly among intravenous drug users) and tuberculosis (Wallace 1990:804, Freudenberg et al 2006:427). It is estimated that, had rates of various afflictions before 1975 continued growing at a normal rate, 20,000 to 52,000 tuberculosis cases would have been averted, as would have 3265 deaths due to homicide, 10,000 HIV infections, 8325 AIDS diagnoses, and 10,357 AIDS deaths (Freudenberg et al 2006:430). Perhaps the most ironic aspect of the “planned shrinkage” policy of New York City is that: “the costs of excess TB and homicide and preventable HIV infection alone were 5 to 15 times greater than the total dollar savings in city expenditures during the fiscal crisis” (Freudenberg et al 2006:430).

Wallace also points out that the destruction of the community and social networks that existed within this area affected the syndemic (Wallace 1990:811). There is no doubt that the massive disruption to the lives of those living in affected areas and the destruction of social networks contributed to levels of poverty and poor physical and mental health. Wallace shows undoubtedly in this case that changes in public policy structure led to community destruction and a syndemic of intensified deviant behaviour, poverty and contagious urban decay, which operated synergistically with, and led to, an excess of biological pathologies, such as tuberculosis AIDS (Wallace 1990:801).

The definition and solidification of syndemics as a concept was developed most notably by Merrill Singer in the 1990s (Singer 1996). Singer (1996) found that previous notions of substance abuse, violence and AIDS (SAVA) as separate phenomena were inadequate in explaining the complex interrelationships between a wide array of political, economic, and social factors and health. As Singer and Romero-Daza state in a later piece about the SAVA syndemic:

> Violence, substance abuse, and AIDS, in this sense, are not concurrent in that they are not completely separable phenomena. Rather, they emerge in the lives of participants in our study as closely intertwined threads in the often tattered fabric of their daily lives (Singer and Romero-Daza 1997:1).

The syndemics approach skyrocketed in popularity and legitimacy with the establishment of the Syndemics Prevention Network by The Centers for Disease Control and Prevention in the United States in 2001. The purposes of the Network include exploring the use of a syndemic framework to study community health and community health initiatives (Centers for Disease Control and Prevention 2005:1). The Network links scholars, health practitioners, community leaders, researchers and anyone with an interest in syndemics, and it will be interesting to see the results of such a large-scale level of networking and communication with respect to community health projects, particularly in the United States.

Recent work in syndemics worth mentioning here is that of Singer et al (2005), which examined understandings of sexually transmitted diseases (STDs) in specific social and cultural contexts. This research is particularly interesting as it shows the bond between non-biological cultural factors and biological pathologies, and will be explained thoroughly here as an example of the importance of cultural understanding when understanding disease
patterns. The authors examined “an STD syndemic (STDS) involving several co-morbid diseases rooted in the social conditions of poverty and racial discrimination” (Singer et al 2005:2011). In particular, this syndemic includes three epidemics in the “low-income, inner city ethnic minority neighbourhoods” of Connecticut, namely those of gonorrhea, chlamydia, and AIDS (Singer et al 2006:2020). The key factors accounting for increased rates of STD transmission, particularly that of AIDS, was not linked with injection drug use, but rather with co-infection with another STD. The latter increases the probability of HIV transmission during sexual contact, along with having multiple sexual partners (Singer et al 2006:2012). Therefore, as these three STDs are operating synergistically to create an excess burden of disease in this population, they can be considered a syndemic. Through focus group discussions with members of affected ethnic minority groups, and in-depth life history analysis, it was found that socialization and cultural context contribute most profoundly to the success of this syndemic. More specifically, attitudes toward sexual infidelity, even in committed relationships, proved to be significant because some sexual relationships were linked to access to resources such as money, and attitudes toward condom use (Singer et al 2006:2016).

Norms regarding condom use are closely linked with ideas of trust. In casual relationships, condom use is regarded as mandatory, even though situational circumstances in the heat of the moment may not result in a condom being used (Singer et al 2006:2016-2017). Condom abandonment usually comes quickly (within one or two months) in relationships that are viewed as long-term with individuals that seem healthy, as the cultural logic system (Singer’s term) links condoms with a lack of trust in such situations, and familiarity is linked with trust (Singer et al 2006:2017). Additionally, women were sometimes found to accept condom abandonment for fear of losing their partner (Singer et al 2006:2017). Partners were determined to be healthy based on their street reputation (whether they were known to have numerous sexual partners without using protection) and general appearance and hygiene (Singer et al 2006:2018). Therefore, it was found that within this cultural and social context, individuals thought in terms of who is “safe” as opposed to what behaviour was “risky” when deciding on relationships, and the type of relationship (whether long-term or casual) was most important in determining if a condom would be used, more so than condom availability (Singer et al 2006:2019). Moreover,

…relationships in which condoms are not used are multiple, overlapping and sequential. The result is a high level of risk for STD. This risk is not random or meaningless; it is conditioned by socioeconomic factors that press participants to focus on short-term pleasure and emotional and material gains rather than on long-term planning and monogamous partnerships. It is, in short, a rational response to social disparity (Singer et al 2006:2019).

Singer et al (2006), along with the other examples mentioned, not only demonstrate the importance of cultural context and socialization in understanding syndemics but also show how to effectively combat them through public policy.

Syndemic theory provides a remarkably holistic way of looking at disease that enables researchers to broaden the scope of what is relevant to understanding disease patterns in society. However, there is the risk of being too inclusive with respect to social aspects of health. Vital to examining diseases properly using this framework is not only to include the appropriate social determinants of health and biological afflictions, but also to exclude those that are not involved in the syndemic. This discrimination is important not only in ensuring research is done
efficiently, but also when utilizing a syndemic framework to improve the efficacy of current public health policy and determining the allocation of government resources.

**Syndemics and Tuberculosis**

Tuberculosis is well known to be an opportunistic disease, affecting those already biologically compromised. In Canada, the majority of tuberculosis cases are found in the provinces of Ontario, Quebec and British Columbia in the foreign-born population (Blackwood et al 2003:2). By contrast, in Manitoba the majority of cases reported and registered in the Manitoba Central Tuberculosis Registry in Winnipeg occur in the Canadian-born population, with the highest rates among treaty Aboriginals (Blackwood et al 2003:2). As of 1996, treaty Aboriginals comprised only 8.9% of Manitoba’s population (Blackwood et al 2003:2). From 1992-1999 in rural Manitoba, the majority (80.2%) of cases were in the Canadian-born treaty Aboriginal population, whereas in urban Manitoba (namely in the capital of Winnipeg), most cases (44.7%) occurred in the foreign-born population (Blackwood et al 2003:6).

Tuberculosis may represent an excellent biological vehicle through which to begin to examine possible relationships between social and biological afflictions in a community. This is because high rates of tuberculosis indicate the weakening of the immune system due to factors such as poor living conditions, overcrowding or lack of access to healthcare. In New York City during the 1975 Fiscal Crisis, for example, homeless shelters served as the main vehicle for tuberculosis transmission among the poor (Singer and Clair 2003:428). As the homeless population rose, which resulted in an increase in the number of persons in homeless shelters and prisons, so too did the number of tuberculosis cases due to overcrowding (Freudenberg et al 2006:427). Singer and Clair (2003:428) state that the possibility of multiple exposures to the bacterium in overcrowded and poorly ventilated shelters, the likelihood of an already weakened immune system, malnutrition, poverty, discrimination, and limited access to healthcare in terms of both diagnosis and treatment are among the many issues that put the poor at high risk for tuberculosis.

This is but one of many studies that link tuberculosis with syndemics, either explicitly or indirectly (e.g., Farmer 1999, Greene 2004, Farmer 2005, and, for an historical example, Herring and Sattenspiel 2007). Clearly, this is not a disease that thrives in the absence of concurrent biological and social afflictions. As stated by Farmer (1999:13):

> Take tuberculosis, with its persistence in poor countries and its resurgence among the poor of many industrialized nations. We cannot understand its marked patterned occurrence – in the United States, for example, afflicting those in homeless shelters and in prison – without understanding how social forces, ranging from political violence to racism, come to be embodied as individual pathology.

With this understanding of syndemics and tuberculosis, let us now turn to the case of Winnipeg, Manitoba, and the possibility of applying a syndemic framework to the study of health in the downtown core.

**Applying the syndemic to Winnipeg, Canada**

While syndemic studies of Winnipeg do not currently exist, the Winnipeg Regional Health Authority and other organizations have conducted research that considers both biological and social determinants of health. Worth mentioning here is a study commissioned by the Literacy
Partners of Manitoba that explored the link between literacy and health in Manitoba (Sarginson 1997). Not surprisingly, this study found correlations between social factors, such as literacy and unemployment, and poor biological health. Health levels were generally poor in low literacy areas of the province (Sarginson 1997:4). By superimposing literacy levels in Manitoba from the 1991 Canada Census on health regions in the province, Sarginson’s study (1997:1-2) linked social aspects of life with biological afflictions. More specifically, Sarginson (1997:2) found that instances of diseases and epidemics increased dramatically in areas with low literacy rates, violent deaths were more prevalent in areas of low literacy than elsewhere in the province, and hospital usage by children was highest in communities with low literacy rates. While a syndemic perspective was not explicitly adopted for this study, it nonetheless demonstrates the linkages between the socioeconomic and the biological conditions of a population.

The Winnipeg Regional Health Authority

The primary bodies regulating and monitoring health in the province of Manitoba are the 12 Regional Health Authorities funded by the Government of Manitoba (WRHA 2007:1 Figure 2). The Winnipeg Regional Health Authority is comprised of health care providers, management professionals and a board of directors, who are responsible for health care for Winnipeg.

Figure 2  Map of Manitoba indicating the location of the Winnipeg Health Region (Regional Health Authorities 2007:1).
Winnipeg is 606 square kilometers in size and contains 57% of the population of Manitoba (WRHA 2007:1). The city is divided into 12 community areas (CAs), and the main purpose of the Winnipeg Regional Health Authority (WRHA) is to determine which health services are best for each CA through Community Health Assessment Reports (WRHA 2007:1). These reports take a Population Health Approach to thoroughly examine the frequencies of diseases, such as tuberculosis, gonorrhea, and syphilis. They also rate the ‘social determinants of health’ in each CA, such as the level of social support, the level of unemployment and the percentage of immigrants (WRHA 2004a:31-33). This chapter draws on these community health assessment reports to illustrate the utility of a syndemic framework for the Point Douglas and Downtown community areas in the city of Winnipeg.

**The Point Douglas and Downtown Community Areas**

Of the 12 community areas (CAs) in the Winnipeg health region, the Point Douglas and Downtown CAs form the basis for this study (Figure 3). Spatial analysis indicates that they have the highest prevalence of communicable diseases in the city (WRHA 2004a:11). Located in the core of the city, the two areas share a border, with the northern border of Downtown abutting the southern border of Point Douglas (WRHA 2004a:2).

![Figure 3](image-url) Map of Winnipeg indicating the Downtown and Point Douglas Community Areas (modified from WRHA 2007 Community Area Boundary Maps).
The Point Douglas CA is 10.9 square kilometers in size and has a population of 41,378, accounting for 6.3% of the population of Winnipeg (WRHA 2004b:1-2). As the smallest CA in the city, Point Douglas has a disproportionately high share (29.7%) of youth aged 19 and under, and a mid-range proportion (12.6%) of seniors aged 65 and older (WRHA 2004b:3). The Downtown CA is slightly larger, with a population of 75,891, accounting for 11.5% of the population of Winnipeg (WRHA 2004c:1-2). This CA has a mid-range proportion (24.8%) of youth and a mid-range proportion of seniors (13.3%) (WRHA 2004c:3).

**Clustering of Biological Afflictions**

Both CAs represent the highest frequencies of several biological afflictions (Table 1). For 1998-2002, Point Douglas and Downtown had the highest crude rates of tuberculosis (0.26 – 0.55 per 1000 residents) in the Winnipeg Health Region (WRHA 2004a:12). The highest crude rates of gonorrhea, chlamydia, hepatitis B acute, and hepatitis C are also found in these CAs for this time period (WRHA 2004a:11-13). From 1996-1999, chronic health conditions such as diabetes, show higher frequencies for all ages and both genders in the core of the city (WRHA 2004a:9). High prevalence rates of stroke treatment, respiratory morbidity treatment, acute myocardial infarction treatment and death due to ischemic heart disease are also present (WRHA 2004a:8, 26). Not surprisingly, these community areas have among the highest rates of low birth weights in livebirths from 1998/99 to 2002/03, premature mortality in both males and females from 1995-1999, and lowest rates of completed 2-year immunization schedules in children born from 1997/98 to 1998/99 (WRHA 2004a:15-16,25). Lastly, these community areas also had the highest hospitalization rates for mental health disorders for all ages and both sexes during the 2002/03 fiscal year, as well as high suicide rates with respect to the rest of the WHR (WRHA 2004a:21-22). The Point Douglas and Downtown community areas, therefore, not only show the highest rate of tuberculosis in the city of Winnipeg, but also the highest rates of other communicable and chronic health conditions.

<table>
<thead>
<tr>
<th>Biological Affliction</th>
<th>Point Douglas</th>
<th>Downtown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuberculosis*</td>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>Gonorrhea*</td>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>Chlamydia*</td>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>Hepatitis B acute*</td>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>Hepatitis C*</td>
<td>Highest</td>
<td>Highest</td>
</tr>
<tr>
<td>Diabetes*</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Rate of low birth weight*</td>
<td>High</td>
<td>High</td>
</tr>
</tbody>
</table>

**Clustering of Social Afflictions**

Not surprisingly, both Point Douglas and Downtown are considered to have poor social conditions that result in poor health. The Point Douglas CA has a low median household income compared to rest of the WHR (WRHA 2004b:4). The incidence of low income or poverty status in this CA is 41% of the population in private households (WRHA 2004b:4). This frequency is “more than double that for the WHR (20.0%), Manitoba (18.0%), and Canada (16.0%)” (WRHA 2004b:5). This CA also has a high rate of mobility of its residents,
with only 56.2% of residents living in owned housing in comparison to 62.1% of residents in the rest of the city (WRHA 2004b:8-9). With regards to education:

Of all the Community Areas, the Point Douglas CA has the highest percentage of the population 20 years and older with less than grade nine completed (17.0%). Although many in this CA population have high school as the highest level of education attained (43.2%), only approximately 27.0% (of those with high school) graduated. In the WHR, 7.7% of the population has less than grade nine level of education, and another 32.0% has reached grades 9 to 13 with or without a high school diploma (WRHA 2004b:8).

It follows that the unemployment rate of the Point Douglas CA for the population ages 15 and older is the highest in the WHR (WRHA 2004b:8). Finally, this CA is considered to have a lower level of social support than other CAs (WRHA 2004b:10). Social support here refers to the availability of support from family and friends, which has been shown to positively affect health (WRHA 2004b:7). As of 2001, both this and the Downtown CAs (along with portions of neighbouring areas) have the highest percentage of children in single parent families at or below the low income cut-off, as well as the highest rates of senior citizens ages 65 and older living alone (WRHA 2004a:36,40).

Social conditions in the Downtown CA of Winnipeg are similar to those in Point Douglas (Table 2). The Downtown CA represents the lowest median income of the WHR (WRHA 2004c:4). The incidence of low income or poverty status is 40%, following closely the Point Douglas CA (WRHA 2004c:4). Residents of this CA are more mobile than the other CAs as a whole. Twenty-four and a half percent of the population of Downtown moved in 2003, and 55.6% had moved in the five years preceding 2004 (WRHA 2004c:7). In the WHR, only 15% had moved in 2003, and 42.1% had moved in the past five years (WRHA 2004c:7). Downtown has the lowest rate of owned housing in the WHR (34.2%), as most residents of this CA live in rented housing (WRHA 2004c:8). With regards to education:

In the Downtown CA, 12.0% of the population 20 years and older, have less than a grade nine level of education. This is one of the higher percentages among the CAs. Many in this CA population have high school as the highest level of education attained (32.8%), however, approximately 36.0% (of those with high school) graduated (WRHA 2004c:7).

The unemployment rate of the Downtown CA is considered high and the level of social support low (WRHA 20004c:7,9). The Downtown CA differs from Point Douglas in the percentage of recent immigrants and visible minorities. Nineteen percent of immigrants in this CA are considered recent immigrants, meaning that these individuals immigrated to Winnipeg between 1996 and 2001 (WRHA 2004c:4). This represents the highest percentage of recent immigrants in the WHR (WRHA 2004c:4). The Downtown CA also represents one of the highest percentages of visible minorities at 28.1% (WRHA 2004c:4). However, of the 8.5% residents of the WHR who identify themselves as Aboriginal, 17.1% live in the Downtown CA, while 25.9% live in the Point Douglas CA, the highest percentage of all CAs (WRHA 2004b:4, WRHA 2004c:4). The presence of relatively large proportions of Aboriginal people, visible minorities and recent immigrants in these two CAs has raised questions about racism and discrimination relating to social support, employment, and general well-being in the Community Health Assessment Report, but as far as this researcher can determine, these issues have not yet been investigated directly.
Table 2  Selected social determinants of health as defined by the Winnipeg Regional Health Authority in the Point Douglas and Downtown CAs with respect to the WHR.

<table>
<thead>
<tr>
<th>Point Douglas</th>
<th>Social determinant of health</th>
<th>Downtown</th>
</tr>
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<tbody>
<tr>
<td>Low</td>
<td>Median household income</td>
<td>Lowest</td>
</tr>
<tr>
<td>High</td>
<td>Mobility of residents</td>
<td>High</td>
</tr>
<tr>
<td>High</td>
<td>Rate of unemployment</td>
<td>High</td>
</tr>
<tr>
<td>Below Average</td>
<td>Level of social support</td>
<td>Below Average</td>
</tr>
<tr>
<td>Low</td>
<td>Average level of education</td>
<td>Low</td>
</tr>
<tr>
<td>High</td>
<td>Percentage of recent immigrants to Winnipeg</td>
<td>Highest</td>
</tr>
</tbody>
</table>

Clustering of Afflictions – Is there a link? Syndemic Synthesis and Future Research

It is undeniable that the Downtown and Point Douglas community areas of Winnipeg represent a disproportionately high frequency of both biological afflictions and poor social conditions with respect to the rest of the Winnipeg Health Region. Both CAs have a high frequency of multiple health conditions, low levels of income, employment, education, social support, and owned housing. Also, racism and discrimination may be present. While it is undeniable that there are forces at work in these CAs that suggest that these conditions may be operating synergistically, the question that needs to be asked is: are these afflictions, both biological and social, linked together in a clear way such that they affect each other detrimentally? To answer this question, there are several lines of inquiry that need to be explored. It would be useful to examine co-infection rates to determine if diseases are operating synergistically within individuals, not just in the population as a whole. For example, in the work of Singer et al (2006), individuals in the study were afflicted with multiple sexually transmitted diseases. This is the core of the syndemic, as these diseases operated synergistically in the community along with cultural logic systems that enabled them to flourish. Additionally in the case of Winnipeg, a closer examination is necessary to determine if connections exist between the social and biological condition of inhabitants of these CAs, or if this clustering of biological and social afflictions is a random event.

If tuberculosis proves to be part of a syndemic in Winnipeg, it would be vital for future health initiatives to determine which social conditions most enable poor biological health in order to determine appropriate methods of bettering the social conditions that most effect physical and mental health. For example, it may be shown that increasing the number of job opportunities or permanent housing in the area would impact health positively. This follows from Freudenberg et al (2006) and others who noted that, during the New York City syndemics, tuberculosis increased in relation to overcrowding in homeless shelters, prisons and low-income housing due to low employment and a general lack of jobs in the area. Therefore, it may become part of the jurisdiction of the WRHA to work with the business sector to increase employment opportunities for residents of downtown Winnipeg. Also, Rhodes and colleagues note that borders and areas of economic growth constitute social locations of heightened HIV risk, partly due to the social disruption created during periods of transition (Rhodes et al 2005:1029). It follows that vulnerability to other diseases, such as tuberculosis, may also increase during periods of uncertainty and transition, such as migration to a new country or general mobility, both of which are highest in these CAs. Singer and colleagues’ (2006) ideas about cultural attitudes toward condom use and the STD syndemic in Connecticut raise questions of the cultural logic systems of individuals in the Point Douglas and Downtown.
CA.s. Ethnographic and other forms of qualitative research are needed to evaluate whether a similar phenomenon is present and contributing to the transmission of diseases such as tuberculosis. For example, as systems of cultural logic informed decisions regarding condom use in the communities of Connecticut, cultural logic systems may also drive the low immunization rates in children in these CAs. It is entirely possible that the issue here is not a lack of resources (i.e., a lack of doctors in the area to perform immunizations), but a conscious decision of parents not to immunize their children based on their cultural attitudes toward vaccination. The possibilities are many, and further syndemic analysis will serve to narrow the number of possible courses of action. It is also important to examine the availability of health services in these CAs, how these services are utilized and viewed by residents of the area, and to explore the impact of racism and discrimination on individual health.

In sum, syndemics provides an excellent way for anthropologists, health care providers, and health care managers (to name a few) to study health in a chosen geographical area in a holistic way. In this case, the highest rate of tuberculosis in the Downtown and Point Douglas community areas is concurrent with the highest rates of several other communicable and chronic diseases, as well as poor social conditions and possibly cultural logic systems that enable tuberculosis transmission. Further research would serve to determine if Winnipeg represents a tuberculosis syndemic or possibly a random clustering of poor health conditions. If Winnipeg does represent a syndemic, appropriate health initiatives that may have not been considered previously can be undertaken to improve both the social and biological health of Winnipeggers in the downtown core.

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References


Chapter 5
Sorting out TB and Immigration: Politics and Statistics, a View from New Zealand
Julie Park and Judith Littleton

While we were working up the proposal for what became ‘the political ecology of tuberculosis in Auckland’ study, we learned of the marked ethnic gradient in TB cases in New Zealand, and in Auckland. Although the figures differ a little from year to year, the overall picture was that Pakeha had fewer than two cases per 100,000, Maori around 11 to 12, people whose families originated in the Pacific Islands around 35, and ‘Others’ around 75 (Ministry of Health 2002, Sneyd and Baker 2003). All of these categories are, of course, constructions of convenience and the ‘Other’ category is especially diverse as it includes anyone who is not a Maori, Pacific or ‘European’ New Zealander. It may include for example, university staff members from Canada and the US, fourth-generation Chinese or Indian New Zealanders, new migrants from Korea, refugees from any of the world’s trouble spots and their descendants, and many more. Despite this internal variability, the TB notification rate for ‘others’ is consistently seven to eight times higher than the national rate of around 10-11 per 100,000.

Because the ‘other’ category includes a majority of people who were not born in New Zealand, and because the proportion of overseas-born notifications has been rising and has recently averaged 65% of all notifications (Das, Baker and Calder 2006, see Littleton et al. 2008:Table 2 for cross-country comparisons), it is easy to jump to the conclusion that TB disease is being brought into New Zealand by recent arrivals. Winston Peters (Figure 1), then a New Zealand First MP, did just that. He claimed in 2002 that refugees and asylum-seekers were bringing HIV, TB, rubella and infectious skin diseases into New Zealand (Berry and Watkins 2002), in an appeal to a section of Kiwi voters willing to slur people who are not “us”. According to Mr Peters, TB and “other third world diseases” had to be stopped at the border by stopping those people who would bring them in.

Figure 1   Caricature of Hon Winston Peters, Used with permission of Dorking Labs.
During the four years since our project began, similar ideas have been expressed by public figures in the national media. A recent example came from the pen of a former Member of Parliament in the ACT party, Deborah Coddington, who became a senior writer for the monthly magazine, *North and South* (2006:39-47). In an article titled on the cover page, “Asian Angst: Is It Time to Send Some Back?”, Coddington (2006:39) adopted the unmistakable stance of “national manager” (Hage 1998:42) which Peters also espoused. She argued that “Asian immigration” has brought “murder, extortion, kidnapping, assassinations and disease” into New Zealand. She particularly referred to a recent school outbreak of TB where the initial case was a school boy who had been in New Zealand with his family for four years before being diagnosed with tuberculosis. She appeared to assume that a TB ‘test’ in 2002 would have prevented the boy developing TB late in 2005 or early 2006 and also would have prevented the transmission of TB to his school mates (Coddington 2006:45).

Hage’s (1998) work on the way in which “others” are incorporated into the national space as people who are under constant suspicion of destroying or interfering with the way of life of those entitled to membership by birth, provides a framework of analysis for these public statements. He uses the term “national managers” to refer to those who imagine that they have an entitlement to include or exclude others and to define the terms of others’ acceptance within the national space. Embedded in these TB and immigration discourses is a metaphor equating bodily and national margins: a version of the body politic as theorised by Lock and Scheper-Hughes (1987), who built on the earlier work of Mary Douglas (1966, 1973). Refugees, asylum seekers and migrants in general are seen as having the capacity to invade the nation, the body politic, in the same way that TB invades the personal body. As a consequence, attention to control of both TB and migration is directed to the borders: dangerous and ambiguous margins as Douglas demonstrated.

As social scientists who are interested in the critical evaluation of appeals to xenophobia, and racism and discrimination against immigrant groups, as well as in understanding why New Zealand has almost twice the TB notification rate of Australia or Canada, we wished to go beyond the headlines and summary statistics to research the relationships between immigration and tuberculosis. This goal led us in several different research directions. Led by Jody Lawrence, we undertook a systematic survey of tuberculosis in the media (Lawrence et al. 2008). We planned studies with communities classified as ‘other’, specifically of Asian and African origins, as well as with Pacific peoples. We wished to explore their experience of TB and settlement in New Zealand (see Anderson, Lawrence, and Ng Shiu et al., this volume). We undertook a review of the international and New Zealand data on immigration and TB to investigate the relationship between them (Littleton et al. 2008). As a result of this, and provoked by the theme “Beyond Ethnography” for the November 2005 Association of Social Anthropologists of Aotearoa New Zealand Conference, Park and Littleton (2007) argued that, although ethnography is pivotal to our research on tuberculosis, we needed to go beyond some narrower conceptualisations of ethnography in order to sort out the relationships between tuberculosis and immigration and to investigate the social justice issues involved. We argued that we needed a multi-disciplinary, multi-level approach, which we have attempted through the framework of political ecology, and we needed to ensure our research results were addressed to specific public audiences: to engage in public anthropology. This brief chapter draws on and summarises all of this work. This task has been made a great deal easier with the publication, late in 2006, of two key New Zealand public health epidemiology papers (Das et al. 2006, Das, Baker and Calder 2006).
Multi-level and multi-disciplinary

The theoretical orientation of the New Zealand-based Political ecology of TB project (see Littleton and King, Chapter 3) encouraged an approach which was founded in the disciplines of the principal investigators: social-cultural and biological anthropology, history and geography. In addition we found that we needed to draw on epidemiology, public health, medical research in TB, infectious diseases, and immunology, and DNA studies, to know where to focus our research and writing and how to make optimum use of our ethnographic and historical data. We certainly needed to consider the minutiae of everyday life, including material conditions and livelihoods, social relationships and social-spatial networks, peoples’ aspirations, values, understandings and experience, and their exercise of agency. Interactions between this personal level and health systems and policy, the views and values of those who work within them, and a range of other structural features at the regional and national levels linked the personal to the structural dimensions. Settlement patterns of recent migrants, greatly affected by the availability of affordable and, in some cases, appropriate, housing, had a direct relationship to the clustering of TB cases. Popular culture, especially media representation of TB and of the groups thought to be the most affected by it, was implicated in both the personal and structural dimensions. Historical political processes, including transnational and globalising forces, related not just to disease epidemiology and transmission but also to colonisation, immigration, conflict and international markets. Movements of people, whether of international students, migrants, workers or refugees, or New Zealanders who travel, linked the local aspects of personal, social and cultural life to international influences.

Although Mr Peters has been silent on “the diseased immigrant” since his promotion to Foreign Minister, there are many contenders for his role as xenophobia-inciter, Coddington (2006) being among the most recent. Our research project as a whole provides information and perspectives which can be used to evaluate the statements from such figures. This paper is specifically devoted to unravelling some of the issues concerning the incidence rates of TB disease, especially as these relate to migrants, and seeking to understand the social and political implications of these disease patterns and the ways in which these patterns are interpreted. To do this we have had to draw on non-ethnographic research, which led us eventually to a new series of ethnographic questions. Several of the chapters in this volume are responses to these questions.

Statistics

In a nutshell, we found that the problem with the ‘Winston theory’, i.e., that new immigrants bring disease, including TB, over the border, is that it does not accord with either international or New Zealand epidemiological data for tuberculosis. While here and elsewhere approximately 20 percent of new arrivals who eventually are diagnosed with TB (Turnbull 2002) are diagnosed in their first year in New Zealand and might justifiably be thought to have active tuberculosis disease when they crossed the border, many develop TB more than a year after arrival. This suggests that more than 80 percent do not have active TB disease when they first arrive (Das et al. 2006). This pattern is typical of other low-incidence countries (Littleton et al. 2008:Table 3). It strongly suggests that certain aspects of the migration and settlement process and environments in the host country are implicated in the high non-New Zealand-born notification rate in the years after first arrival.

Our first step in seeking to understand this apparent puzzle was to acquire further medical information about tuberculosis, its detection, treatment and prevention and the circumstances
under which a person who has had latent tuberculosis infection (TBI) for many years may
develop active tuberculosis disease (TBD). For this we drew on some of the many public talks
and helpful explanations given by Craig Thornley of Auckland Regional Public Health
Service (see Thornley and Pikholz, Chapter 1), one of the key advisors for this project, as well
as on other written material provided by the Public Health service, and texts on TB (e.g.,

We also read further in immunology. Anything that suppresses a person’s immune response
assists the conversion from latent infection to active disease (McDade 2005). Stressors such
as those incurred by settlement in a new country where the environment is experienced as
hostile, co-infections such as HIV, or non-infectious conditions such as diabetes, malnutrition,
or inadequate housing could all be implicated. Thus it would seem that to prevent TB
disease developing from TB infection, good TB (and diabetes) prevention, timely treatment,
healthy living and working conditions and freedom from discrimination are required, and
once in place these would have the potential to reduce the TB notification rate to a lower level

Using the international literature and examining the logic of possible explanations for higher
rates of TBD in overseas-born people we arrived at four possible explanations that could all
make contributions to the rate. Through its refugee policy, formalised in 1987 as the Refugee
Quota Programme, New Zealand is committed to accepting 750 UNHCR refugees each year.
This number includes around 10 percent who are given priority because of fragile health.
Thus some refugees arrive every year with TBD and are treated on or before arrival, while
others have TBI and are treated or monitored as necessary. There is only one refugee
reception centre in New Zealand, located in Auckland. It caters for all incoming refugees. A
study of refugee health status between 1995 and 2000 suggested that about one-quarter of the
Auckland notifications in the first year after arrival are accounted for by refugees who are
assessed and treated during their six-week stay at the reception centre (McLeod and Reeve
2005). Thus refugees make a small, known contribution to the national rate of overseas-born
notifications in the first year after arrival. However, because all of these new arrivals begin
treatment before they leave Mangere, they do not transmit TB infection.

The other three possible explanations for the higher overseas-born rate are that TBD is not
detected or reported at the time of migration, that it is acquired in the destination country after
migration, or that it is a result of activation of existing TBI. We examine these possibilities in
turn, summarising here the detailed research that we have carried out in the international
literature (Littleton et al. 2008). There are two kinds of indicators of the extent of imported
TBD. One indicator, post-migration health checks, are part of the immigration process in
certain states in Australia (Pang, et al. 2000) and the United States( DeRiemer et al. 1998).
Migrants who are at high risk of particular health problems, including TB, undertake to report
to a health clinic for further diagnostic assessment shortly after arrival in their destination
country. Thus these checks are likely to show a much higher rate of disease than for the
general migrant population. Despite this, these studies suggest that TBD crossing borders
makes only a small contribution to notification rates in the host country. The second
indicator, studies of time between arrival of migrants and diagnosis of TBD shows
considerable variation depending on place of origin (Farah et al. 2005). However in low
incidence countries it is common for about half the cases of TBD in migrants to develop five
years or more after arrival (Littleton et al. 2008:Table 3). Notification within one year of
arrival is potentially an indicator of imported TBD. Quite effective screening is already in
place, especially with the extension in 2005 of mandatory TB screening to all those coming to
New Zealand for six months or longer from high-incidence countries or as international students, and to all others who intended to stay for 12 months or longer (Das et al. 2006). However, short-term visitors and asylum-seekers are not included in this screening programme. A recent study of asylum seekers detected 0.6% TBD ($n=4/900$) (Hobbs et al. 2002), a rate typical of high-risk groups, but not a major contributor to the national incidence. Yet despite this relatively comprehensive screening, overseas-born people undeniably have higher rates of TBD post settlement and 80 percent of these notifications occur after the first year of settlement, suggesting that the disease develops after arrival in New Zealand.

How does this happen? Logically, there are two possible explanations: either the activation of latent infections, or newly acquired infections. Possibly, both explanations could make a contribution, in tandem.

Particular strains of TB have their own genetic fingerprint which can be used to see whether the disease is being caused by strains shared with the host country or by locally unusual or unique strains which are much more likely to have been imported. Where a person has only recently developed the disease after a considerable period of residence, DNA sequences that are unusual for the host community indicate reactivation of an infection that was contracted elsewhere. New Zealand studies are not yet complete, but overseas studies suggest that most of the higher rate in overseas-born people is due to re-activation of TBI in people who were exposed to high levels of TBD in their countries of origin or of long term residence (Antunes and Waldman 2001, Chin et al. 1998, Small et al. 1994, Tornieporth, et al. 1997, Zuber, et al. 1997). We await publication of the New Zealand DNA studies with interest.

These overseas studies also show that migrant and local TB have different epidemiological characteristics and there is little cross-transmission outside the migrant group. Where cross-transmission does occur, it is at a low rate. Although there are exceptions (and the high school case trumpeted by the ex-politician journalist is one), many cases of cross-transmission are, counter-intuitively, from locals to the overseas born, in other words, the reverse of the ‘Winston’ theory. This takes place where the overseas-born are exposed to the same conditions that promote TB in any population: poverty, homelessness, crowding with other infected persons, HIV infection, other illnesses and discrimination (Ho 2003, Jasmer et al. 1997). A study in Montreal (Kulaga, et al. 2002) interpreted clustering of TB among Haitians as activation of infection and transmission within this community which suffered social deprivation. Such conditions also promote within-community transmissions, as shown in TB among some Pacific islands households in Auckland (Ng Shiu et al. this volume, Voss et al. 2005). Calder and various colleagues have demonstrated a number of times that community transmission is very effective in Pacific communities (e.g., Calder et al. 2000, and see Ng Shiu et al., this volume).

It is highly likely that overseas-born people in New Zealand with TBD develop the disease mainly as a result of activation of pre-existing TB infection acquired in former high-incidence living situations, and that this is associated with some, mainly within-community, transmission. However, there are some exceptions to this when the conditions are right for transmission, as a current “atypical” outbreak of TB in a New Zealand boys’ school has demonstrated (Thomas and Ellis-Pegler 2006).

This review has given us a firm basis to direct our ethnographic enquiry in Auckland and our historical work in New Zealand. As prefigured in the introduction, it has reinforced for us the importance of our ethnographic and historical enquiry, reported in several of the chapters in this volume. We have asked, and partially answered: What is it about the ecology of some
groups in New Zealand that promotes conversion from TBI to TBD and intra-group transmission of TBD? We do not accept that conversion of TBI to TBD is a ‘natural’ process. We see it as socially engendered and not inevitable.

While it is common, and well-attested, to link TBD to poverty as well as migration (e.g. Martin 2000, Thomas and Ellis-Pegler 2006), poverty is a very broad brush. Hence we have enquired into the ecologies of TB, including the life stories of migrants, their living situations, their social networks, understandings and experience of general health and TB, interactions with the health services, and so on. We are interested in how these features interact with poverty, crowding, changes to payment for health services and threats of deportation, as well as to less material noxious social conditions, that all act and interact as stressors, and how these patterns map onto the Auckland landscape.

Some people experience severe difficulties of acceptance within their own communities because of TB, or conduct their lives with TB to avoid this anticipated stigmatisation. This has implications for diagnosis, treatment, recovery and infection of others. Certain groups, such as ‘Asians’ or ‘refugees’ or ‘Muslims’, are stigmatised and singled out for discrimination, even without TB. Combined, these experiences have the potential to increase the vulnerability of migrant groups to disease.

Conclusions

Screening and treatment at the border is of continuing importance, but so is long term, accessible and affordable health care, as Thomas and Ellis-Pegler (2006) point out. This is because only about 10-11 percent of TB is diagnosed by systematic screening (Littleton et al. 2008:6), and 80 percent of TB in immigrants occurs after 12 months and up to 20 years after arrival. Therefore diagnosis is usually reliant on the primary health care system, given this long term vulnerability to reactivation of TB.

Good and timely treatment is part of the transmission-prevention strategy. But better conditions in New Zealand for the overseas born have the potential to mitigate the consequences of a history of exposure to TBI and help prevent the activation of TBD as well as its transmission. One stressor experienced by particular groups is their continual exposure to racist slurs and ethnic stereotyping, including being singled out as potential threats to the New Zealand way of life and health by public figures. As we began our study Winston Peters was the main perpetrator. As we completed it, others have taken his place. Such a stressor is more likely to increase the rate of conversion of TBI to TBD than to prevent the importation of TBD into New Zealand. It gives permission to other New Zealanders to continue well-documented discrimination in employment and rental housing, for example, which also reduce the life chances of migrants (Bedford et al. 1995, and see Lawrence and Anderson, Chapters 16 and 17), and to engage in the everyday harassment of egg-throwing, shouted abuse and physical violence -- apparently part of the New Zealand way of life -- reported against Koreans in the South Island city of Christchurch by Chang et al. (2006) and against Anderson’s participants in Auckland (2007). In this context a broad, multi-disciplinary approach is powerful and enables us to speak to public questions of social justice and to create a greater understanding of the challenges facing migrants, the health service and all New Zealanders. We can also suggest that every threat against migrants to curry political favour or to increase the sales of glossy magazines has the potential to promote TBD in the overseas-born, on the basis that the cumulative effect of always being cited as a social threat is a high level of sustained stress, and hence lowered immunity.
References


Notes

1 New Zealand is fortunate in its low HIV co-infection rate (Thomas and Ellis-Pegler 1997) and its low rate of multi-drug resistant TB (Cameron and Harrison 1997). However, in a recent editorial in the *New Zealand Medical Journal*, two experts in the field, Thomas and Ellis-Pegler (2006), suggest that a larger HIV co-infection rate may be on the horizon. Diabetes is currently, however, a major New Zealand health problem. Diabetes is estimated to affect between 125,000 and 200,000 people out of a population of just over four million (Ministry of Health 2006; Diabetes New Zealand 2006) and its role is worth further study, particularly as Maori, Pacific, Asian and Middle Eastern people tend to develop diabetes earlier than do Pakeha. In addition, a recent study of death certification suggests that there is a large (x6) under-recording problem for diabetes in the mortality statistics (Chen et al. 2004), so its implications for TB may be underreported also.
Chapter 6
An Empowerment Approach to Raise Awareness about and Reduce Stigma around Tuberculosis among the Indian Community in the Auckland Region.

Jill Miller

In New Zealand, and particularly Auckland, ethnic health disparities have increased in recent years and people of Asian, Indian and African descent described in the NZ census as “Other” ethnicity have 35 times the rate of TB than that of Europeans in NZ (Das, Baker and Calder 2006). TB affects the most vulnerable populations and can be a significant problem amongst children.

One of the major challenges the staff of the Auckland Region Public Health Service (ARPHS) have observed during their work with TB cases, contacts and the community is the stigma associated with the disease. The stigma of TB is powerful because of the strong public fear of infectious diseases. Lack of knowledge about TB fuels this fear and many people continue to be unaware that TB is curable. Often, cancer is more socially acceptable to many people of Indian, Asian or African ethnicity. TB patients often endure more than physical symptoms and suffer from emotional distress because of the stigma imposed by society and rejection by family and friends. This rejection and shame often prevents people seeking treatment and completing treatment once it has been commenced (WHO 1998). One study concluded that there were major cognitive/affective reactions to TB such as personal threat, social rejection and social stigma (Westaway 2004).

The ARPHS is responsible for TB control in the Auckland region. This includes treatment supervision, contact screening and follow up of people who have had contact with cases, and an immunisation programme against TB (BCG vaccination). Since 1998, ARPHS has participated in yearly projects with various ethnic communities to raise awareness of TB, reduce stigma and correct false information.

In this chapter I describe the background and rationale for one such programme, the frameworks and methods used, the participants, and present an evaluation of its effectiveness.

TB and the Indian Community

During the years 2004-2005, 199 people of Indian ethnicity were diagnosed with TB in Auckland (Thornley 2005). In Auckland between 2003-2005, a quarter of all TB cases were of Indian ethnicity; the largest single group contracting TB.

Following review of the 2003-2005 statistics it was decided to offer an education programme to the Indian community. It had been noted, in particular, that very negative attitudes to TB had been observed amongst the Indian population. There had been several incidents where these negative attitudes and beliefs resulted in tragic outcomes, including death, as frightened people avoided medical consultation and treatment. These fears were fuelled by the belief that TB cases would be ostracised by the community because of their diagnosis.

According to research on TB in India, Indian families and communities often have a limited knowledge of TB. Causes of TB are held to be ‘germs’, poor nutrition and physical exertion, and TB is commonly thought to be spread through contact and contamination (Uplekar 1996,
Nair 1997, Geetakrishnan 1988, Purohit 1988). Fear often results in communities physically isolating patients. It has been noted that there are differences in experiences of stigma, particularly for women and this has resulted in social barriers to treatment (Ogden 1999).

A diverse range of attitudes and beliefs, and difficulties in adhering to treatment amongst some Indian patients had been observed by PHNs working at ARPHS. Similar difficulties had been encountered amongst other ethnic groups including Chinese, Somalian, and Pacific Island communities. Although often not formally evaluated, it is generally agreed amongst health professionals that TB awareness programmes have resulted in improved knowledge, acceptance, higher immunisation rates, greater understanding and cooperation (Worth, Denholm and Bannister 2003, Bedasso 2002). Consequently a programme targeted at the Indian community (including locally and foreign born people from both the subcontinent and Fiji) was developed

Frameworks

Successful programmes require appropriate frameworks to guide and support strategies. The principles utilised to support this project were the Treaty of Waitangi1 and the Ottawa Charter. Current policy interpretations of the Treaty of Waitangi have distilled the principles of partnership, participation and protection (Orange 1987, see Oh this volume). Partnership refers to the long-term ongoing relationship between the Indian community and ARPHS. It also refers to equal stakeholding from the initial stages of the project, progressing through to ownership by the Indian community, with the provision of support as required from the project team.

Participation emphasised the involvement of all the Indian organisations as stakeholders in planning, training, delivery, implementation, monitoring, eventual ownership and evaluation of their own TB awareness programme.

Protection was the need for providers to be pro-active in health promotion activities and the development of preventative strategies. This entails the additional resource use that may improve Indian health status particularly when related to TB. This also was mindful of the rights of the NZ public to be protected from TB.

The Ottawa charter provided a framework to support our health education/awareness to the community. The Charter for Health Promotion was developed by the World Health Organisation in 1986 to provide a framework for action to promote health with the aim of enabling people to increase control over and improve their health (Beaglehole, 1993). The Charter identifies five broad areas for action that, together, comprise a comprehensive strategy for achieving this outcome. They are:

- Building healthy public policy;
- Creating supportive environments;
- Strengthening community action;
- Developing personal skills; and
- Reorienting the health services (Auckland Regional Public Health Service 2003)

These goals framed the programme delivery of health education to the Indian community
Programme objectives

The first step was to provide a teaching programme that enabled participants to gain knowledge about TB, and then the knowledge they had gained about TB could be disseminated to the Indian community in the Auckland Region.

The objectives were that by the end of the training module the ‘train the trainer’ participants will:

- Have attended all four training sessions;
- Have gained knowledge and understanding about TB and the key TB messages;
- Have gained the personal confidence and skills to be able to present and disseminate information about TB to individuals and groups within the community; and
- Provided evaluation and feedback about the training programme in order that future programmes can be enhanced and improved.

Programme Content and Delivery

The programme was facilitated over four consecutive two hour training sessions. The length of these sessions was considered to be an optimum time frame in order for content of the programme to be absorbed and retained by the participants. All sessions took place in a conference room within the ARPHS complex. The venue was located on a bus service route and car parking was available on site. The room was spacious, comfortable and considered conducive for learning. Light refreshments were provided and available to help participants relax and feel comfortable. Prior to the commencement of the sessions networking and discussions took place between trainees and trainers.

The trainees were invited to participate by TANI (The Asian Network Inc. – an umbrella community organisation aimed at social development) and included members from the Probasi Bengali association, Sikh Womens’ association, Waitakere ethnic board, Shanti Niwas, the Auckland Indian association, Bhartiya Samaj, Kannada Koota, SWAASTHH and TANI. These are all diverse Indian groups that regularly meet individually within the region. The attendees from these groups were two-thirds male and one-third female with ages ranging between 18 and 65 years. The youngest trainees were university students and other participants included doctors, refugee workers, retired people and community workers.

The trainers were drawn from the ARPHS workforce and consisted mainly of public health nurses supported by a Medical Officer of Health and an Indian community worker. The PHNs were all middle aged women, the Medical Officer a male in his mid thirties, and the community worker a male in his late forties.

The content was directed towards the main objectives. The first was to educate participants about TB and secondly to demonstrate to trainees methods to deliver presentations to their community groups. Each of the sessions included a wide variety of activities, and trainees were encouraged to participate in each activity. This variety of activities aimed to keep the participants stimulated and fully engaged throughout the process. The ‘hands on’ approach sought to encourage attendees to be engaged in an active learning process. Formal lectures were kept to a minimum and presented by the Medical Officer of Health, who discussed TB epidemiology, trends amongst the Indian community etc. Repetitive key TB messages were delivered using a diverse range of methods. These included the use of flip charts with pictorial illustrations (Figure 1), role plays, quizzes, discussions, case studies, videos, presentations
with peer review, group work and referring to the TB manuals. These manuals were compiled by the PHNs prior to the sessions and consisted of basic TB information. They were issued to each participant as tools to enhance community presentations.

![Figure 1](image.png)

**Figure 1** An excerpt from the flip charts used in public health presentations.

Most presentations followed the KISS (Keep it Simple Stupid) principle where information was delivered initially in a simple format, which could then be expanded or broken down further depending on the ability and learning style of the group members.

Sessions took place in a friendly, fun and sometimes competitive manner, encouraging participants to work together and provoke questions or stimulate discussions relating to TB. These activities, which aimed to prepare participants for their community presentations, provided a safe but realistic environment in which to practise their talks and gain confidence in presenting the material in public. Participants were always given the opportunity to ask questions after or during the activity. This enabled affirmation and confidence building and minimised confusion or misunderstanding by trainees. Trainees were told at the beginning of the programme that every question was important and that they would be given answers. All questions were answered in a positive and constructive manner encouraging participants to feel safe, valued and willing to ask further questions as they arose. At the conclusion of the programme participants were all acknowledged at a graduation ceremony where they were presented with individual certificates. Many participants were very proud of this achievement and had invited family members to attend and support them.
It was imperative throughout the programme to develop and maintain positive, respectful and friendly relationships with the participants. At each session trainees were acknowledged on arrival and at the conclusion. The public health nurses made themselves accessible to the participants by providing contact details and offered ongoing support for future community presentations. In the early stages of community presentations this support was sought and given but as the trainees developed confidence only additional written resources were requested.

Programme Outcomes

The TB awareness programme was specifically an Indian community project, which aimed to reduce stigma, heighten awareness of TB and encourage BCG vaccination for Indian neonates. It was intended to motivate community members to access early medical intervention and encourage and orient health providers towards early diagnosis and appropriate referral for investigations and treatment. The trainees conducted their presentations within their own organisations. The activities were safe and culturally appropriate and offered opportunities for participants to meet together with other Indian groups they would not have normally had contact with.

This enabled people to develop their self confidence and awareness within the diverse Indian cultural contexts present. Coming together in this way created some issues in group dynamics relating to power and control, and gender. These were addressed and by the final education session attendees worked together towards a mutual goal.

In the short term the intention was to develop a ‘Train the Trainer’ programme. The trainees successfully acquired the necessary skills that enabled them to educate their communities about TB by delivering key messages and promoting early vaccination. There were 46 awareness workshops delivered throughout the various community groups within the contracted time frame from 9th February until June 30th 2005. The average attendance at the workshops was 25. These attendees were members from within the group of the person presenting the programme, or interested invited friends.

Media (in the form of newspaper, radio and TV) were fully utilised to ‘spread the word’ in the following ways. The TB key messages were delivered through the majority of Indian newspapers and community newsletters. A 30 second TB educational advertisement was developed and played at regular intervals on Radio Tarana, a leading Indian radio station. A film was developed and played on Triangle television that portrayed a young Indian man successfully completing TB treatment and leading a normal life.

These activities resulted in the community receiving positive key messages, having increased knowledge and developing positive attitudes.

Building Healthy Public Policy and Creating Supportive Environments

In the long term, the programme was intended to develop community empowerment and promote ownership of the project, as outlined in the Ottawa Charter. The programme contributed to the development of strong ethnic communities both in terms of formal associations and informal social networks. The community worked alongside other agencies in an attempt to reduce the socioeconomic disparities that contribute to the increasing number
of TB cases. TANI became aware of the importance of intersectoral collaboration and how to access Housing New Zealand, Work and Income, and the health sector.

The development and implementation of healthy public policies reflects intersectoral collaboration. TANI now has improved working relationships not only with health, but also education, labour, commerce, housing and other sectors that have influence on the health of the Indian community. TANI has been a strong advocate in the area of housing. These efforts are directed at alleviating and preventing unsatisfactory housing conditions. Sub-standard conditions may lead to the immune system becoming suppressed or facilitate the transmission of the bacillus, increasing the rate of TB. Education can assist to increase knowledge about nutritious diet that will avoid under-nutrition, which may also contribute to weakened immune systems.

Healthy Public Policy related to health services means unrestricted access to medical services and free investigations and treatment for TB. This ensures early diagnosis, the prompt commencement of anti-microbial medication and the full completion of treatment. In 2005, when the Indian awareness programme was in progress, this was in fact the case. Since this time there has been a change in immigration policy and access to healthcare is not always freely available. Ongoing education of the policy makers in the health and immigration sector is paramount. It is essential that ‘Healthy Housing’ projects are continued and extended to ensure Indian people are housed in optimum conditions, preventing the risk of communicable disease occurring. Research has proved beyond doubt that poverty and unhealthy housing makes people sick (Woodward 1998).

Developing personal skills and strengthening community action

The development of personal skills was one of the major successes of the education programme. All participants developed knowledge, confidence and skills to deliver TB education programmes to their community. TANI was very keen to utilise this same model to develop and deliver other health programmes to their people. The trainees became tolerant and respectful of each other and learnt skills that enabled them to work alongside each other. With the strengthening of community activities, the knowledgeable Indian participant was able to take ownership of the content of the programme and cooperate with TB control measures and activities. This ensures that Indian clients can now cope more easily with the impact of TB disease and cooperate with treatment.

The re-orientation of health services

Health providers from Auckland who attended seminars were educated about the occurrence of TB in the Auckland region. They were encouraged to consider TB as a diagnosis and made aware of the past issues of delayed diagnosis. They were made aware of the need to advise, support and protect family members and community involved with a TB case. Primary health providers, hospital staff and other health professionals were made aware of the current trends in TB, through articles written in Public Health Advice (an ARPHS bi-monthly magazine providing advice to primary health providers) and various seminars that were made available in 2005. These also outlined the latest drug regimens, diagnostic measures and the importance of completion of prescribed treatment. Education was available about the world health strategy of the use of Directly Observed Therapy Short course (DOTS), in order to obtain a
complete cure (WHO 2006). Information about the DNA fingerprinting test which links TB cases to each other was also discussed.

The cardinal principle of health promoting programmes is empowerment. The awareness programme sought to empower by the provision of relevant, accurate TB information, enabling Indians to develop skills and a healthy level of self-esteem. Many attendees demonstrated visible growth in their teaching skills and self confidence. The provision of excellent preventative services, the shaping of a healthy environment through robust health protection, and advocating for healthy public policy all contribute to this ongoing process.

**Evaluation of the Programme**

We utilised formative evaluation to measure progress towards the achievement of the overall aim and objectives (Casswell 1999). This was carried out by evaluating the programme during the planning, implementation and development stages, making adjustments and improvements while in progress. Regular meetings between public health staff, educators and organisers ensured the continuous review of progress. Refinements were made and all issues arising were addressed.

Each participant was given an evaluation form to critique each session and their overall satisfaction of the programme was measured. The feedback was exceptionally positive and offered no constructive advice on how the programme could be improved. This could have been a result of participants being uncomfortable about offering feedback and is an issue that will be carefully considered with future programmes.

Overall the programme was successful and the model will indeed be replicated and utilised in future TB awareness programmes. A report from the community and TANI was received and was positive. Recommendations were that the time frame was too short and that the project would have been more effective with more time. It suggested that future programmes dealing with health issues should continue and that additional funding would be useful in ensuring programmes were effective.

At our request, an independent evaluation was made by an attending anthropology Ph.D. student. This was a very comprehensive document and will be an important tool for programme planning in the future. Her conclusion was that the programme achieved its objectives by providing well structured workshops that educated community members about TB enabling them to disseminate that information into their local communities.

The Communicable Disease Control team is endeavouring to secure permanent funding, in order to replicate the programme and roll it out to other “at risk” communities in the future.

**Conclusion**

Some lessons learnt for future programmes include the importance of having sufficient time for planning, implementation and evaluation and access to adequate funding. It is important to acknowledge people’s cultural beliefs, values and practices as well as their prior experiences in planning programme structure.

The use of frameworks in promotion programmes are invaluable because they support strategies providing structure and direction for the project team to work from.
The programme has been successful in heightening awareness and reducing stigma associated with TB. Although not formally evaluated in relation to outcomes, anecdotally the PHN group have observed positive attitudes amongst newly diagnosed Indian TB clients, who often recognise, relate to and understand educational resources that are utilised.

Acknowledgements

The author would like to acknowledge Dr Lester Calder, formerly of ARPHS, who initially introduced TB awareness programmes to different groups.

References:


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Notes

1 The Treaty of Waitangi signed in 1840, between the Crown and Maori, established the fundamental basis of a contractual relationship.
Chapter 7
The Treaty of Waitangi Principles in He Korowai Oranga – Maori Health Strategy: A Critique from the Perspective of TB Care
Moana Oh

Tuberculosis has been a significant killer of Māori. Anecdotal reports indicate Māori communities were ravaged by the disease throughout the nineteenth and early twentieth century, prior to the collection of statistical data (Bryder 1991:109). Although the incidence of TB amongst Māori has reduced significantly, current rates of TB remain twelve times higher than those of Pakeha.

Improving poor Māori health status has been a policy objective of the New Zealand government over the last two decades. Various political strategies have attempted to address economic, social and cultural determinants which influence health outcomes. Central to current government Māori health strategy is the referencing of Māori cultural concepts derived from the 1840 document, the Treaty of Waitangi.

The manner in which the Treaty of Waitangi has been interpreted historically has rendered many Māori impoverished and susceptible to infectious diseases like TB. Similarly, how the Treaty principles are applied and interpreted within the health sector has direct bearing on health outcomes and experiences of health service users who are Māori and have TB.

This study considers the use of the principles of the Treaty of Waitangi in He Korowai Oranga - Māori Health Strategy (2002) and whether the principles influence the shape and effectiveness of health services to Māori with TB. TB provides a useful lens through which to consider health services because of the length of treatment and the different levels of interaction with healthcare professionals and services within the health care system.

Background

Māori are the indigenous people of New Zealand, comprising almost 15% of the population. Like other colonised people, Māori remain on the economic fringes, located predominantly in the lower strata of employment, education and income. In 2001, the average individual income in New Zealand was $24,000 per annum, yet 56 percent of Māori adults had an income of less than $15,000 p.a. (Te Puni Kokiri 2001).

In New Zealand, as is the case elsewhere, poverty remains the single most important determinant of ill health, determining life expectancy and morbidity (Hofrichter 2003:1-3). A key determinant of poverty amongst Māori has been the lack of recognition of property rights and settler control of institutions that have distributed property rights since the Treaty of Waitangi (Libecap 1989:1).

The Treaty of Waitangi was signed in 1840 by Māori and representatives of the British Crown. Although the Treaty focused predominantly on property rights - acknowledging sovereignty, citizenship rights and existing native title, contemporary interpretations have widened the scope of application. The main drivers behind this broadening of Treaty interpretations have been the Courts and the Waitangi Tribunal.
The Waitangi Tribunal was established under the Treaty of Waitangi Act (1975) to investigate Māori Treaty-based grievances. While the Tribunal recommendations are not binding on government, Tribunal findings do influence Treaty jurisprudence, with the Courts acknowledging that “the opinions of the Waitangi Tribunal are of great value to the Courts” (New Zealand Māori Council v AG [1987] 1 NZLR 641, 664, per Cooke P).

The Tribunal’s “findings and recommendations [are] expressed in the currency of Treaty principles” (Hayward 2004:29). Derived from the underlying tenets of different Treaty versions, Treaty principles are not intended to supplant the Treaty, but rather to inform its application in contemporary circumstances. However, there is no universal agreement as to the exact meaning of the principles and it is not known if all possible interpretations of the Treaty have been identified. Experts agree that the evolution of principles is dynamic and ongoing; therefore, the compilation of a complete and comprehensive list of principles may never be possible (Hayward 2004:29-40, Orr quoted in Hayward 1997:475, Durie 1998:29). These and other characteristics of the Treaty principles have generated considerable and often divisive debate.


Ironically, a key motivator for incorporating Treaty concepts into policy was the desire to develop policy relevant to the needs of all New Zealanders. In 1988 a Royal Commission on Social Policy concluded that “few if any aspects of well-being could be seen to stand outside the Treaty” (1998:42). The Commission identified three Treaty principles - partnership, participation and protection - as relevant to the future development of social policy (1988:49). Despite continuing disputation surrounding the Treaty and Treaty principles, these three principles now frame recent Ministry of Health policy targeting Māori.

The goal of He Korowai Oranga – Māori Health Strategy (2002) is ‘whanau ora’ or the health and well-being of family. Policy strategies are structured according to the generally accepted interpretations of the principles. Partnership is envisaged as a process of Māori and regional health authorities - the District Health Boards (DHB) - working together; participation refers to enablement of Māori within and across the health sector; and protection is akin to a fiduciary duty, construed as a duty of health services to recognise and respond to Māori cultural beliefs, values and practises (Ministry of Health 2002a). Applications of the principles within the policy frequently overlap, interrelate and underpin the interpretations of other principles.

While He Korowai Oranga has been positively received by many groups working in the Māori health sector (Ministry of Health 2005), the interrelatedness of the policy structure suggests that clear evaluation of the effectiveness of a Treaty principles framework in Māori health strategy is difficult - particularly as the strategy is supply-side focused. Other factors challenging the efficacy of the policy are existing medical, organisational and racial cultures within health services, and low levels of Treaty awareness (State Services Commission 2004:5, NBR 1989), especially regarding the relevance of the Treaty to health service delivery, within some DHB (Waikato DHB 2001:7).
Given the apparent limitations of *He Korowai Oranga* and the contested interpretations and expectations surrounding the Treaty, the focus of my research was to consider what Treaty principles mean in Māori health policy and what does the presence of Treaty principles deliver to Māori health service users with TB?

**Methodology**

Information for this study was gathered from semi-structured interviews with Māori participants (n=10) who had been diagnosed with TB within the Auckland Public Health Region from 2002 to 2005. Participants have considerable experience within the public health sector as treatment for TB often requires hospitalisation and a lengthy period of drug therapy. Participant ages ranged from 22 months to 72 years, and comprised four males and six females. Six participants had pulmonary TB, three had extra-pulmonary TB and one case was a reactivation. Four participants had full-time employment and five received some type of income support. Only one person had a tertiary education qualification.


**Results**

The results are divided and presented under each of the Treaty principles. Each section is then categorised, where applicable, according to key Treaty principle concepts. The interpretation of each concept is briefly outlined to guide the reader through the analysis process. However, it is important to acknowledge that the interconnectedness of Treaty principles mean that some themes could be categorized under more than one principle. The key themes identified were treatment compliance, patient-doctor relationships, stigma and culture.

**Principle of Partnership**

In nearly any context, the term partnership is conceived of as a collaborative process. That is, a formal relationship established between organisations or individuals, who co-operate in a shared activity toward a common purpose. Each group is assumed (by the other) to be acting in ‘good faith’, for the mutual benefit of both groups and with an acknowledgement of a duty to consult each other regarding activities which influence their common goal (Te Puni Kokiri 2001:78). *He Korowai Oranga - Māori health policy* envisages a partnership between Māori (through Māori health service providers) and government agencies, for the purpose of achieving *whānau ora* ‘healthy families’.
Treatment partnership – case managers and patients

Under the policy, health agencies and providers assume responsibility on behalf of the Ministry of Health as the ‘partner’ within the treatment partnership. In the TB treatment process, the case managers (the public health nurse and clinician) are the government representatives in partnership with the person diagnosed with TB.

Within the treatment partnerships in this study, medical professionals received mixed reviews from participants. Whilst clinicians generally were considered very favourably, public health nurses (PHNs) were the most positively evaluated. All study participants described PHNs as supportive, informative and caring throughout patient treatment.

Other medical and nursing professionals were perceived by seven participants as less accommodating of individual differences, patient expectations and circumstance. For example, one participant said a staff nurse ‘gave him the feeling’ it was his fault he was sick. The same participant’s partner also mentioned the different approaches of district health nurses.

…one of the district nurses that came to change his thing [dressing], it was sort of like, straight in, do her thing, never mind having a talk to see how he actually is. You know, change his dressing and off. Whereas another one, use to come in and have a cup of tea and shall we get your dressing changed now, you know, making him, comfortable in his own place, whereas the other one, hmm…(Manaia, partner of Hone).

Manaia’s observations indicate maintaining consistency of service delivery amongst often autonomous health professionals remains an issue in the development of effective TB treatment partnerships.

Good faith = Duty of care?

In Treaty jurisprudence, good faith is understood as a duty to act reasonably, honourably, respecting each others respective interests or views, and acknowledging some degree of accountability between partners (Waitangi Tribunal 1998:27-30). An analogy can be drawn between the good faith expectations of Treaty partners and that of patient expectations for a duty of care from health professionals.

A duty of care means there is an expectation health professionals will exercise a reasonable standard of care while performing any act that could foreseeably harm patients (Medical Council of New Zealand 2004). That is, timely and appropriate care, as well as complete and comprehensible information about intended treatments.

…they [hospital medical team] weren't even breaking their big words down for me. As much as I asked them, arr look, can you explain that better? I can't understand your medical terms. They couldn't do that (Kowhai, aged 24yrs).

Kowhai’s lack of understanding of her TB illness and treatment was one of the reasons for her absconding from hospital whilst still infectious. Patient adherence to TB treatment relies on key health professionals establishing good communication with their patient (Currie et al. 2001, McLean 2002). Other participants had similar difficulty understanding their doctors’ explanation of their TB treatment.

Three participants had instances of inappropriate treatment and/or delayed TB diagnosis. One individual was prescribed twice the recommended medication dosage, another claimed
delayed TB diagnosis and inappropriate treatment triggered a psychotic episode, while another contracted TB meningitis after laboratory results were mistakenly not sent to her GP.

These results indicate there are still some significant challenges in TB diagnosis and treatment with regard to minimizing preventable harm to patients and reorienting health services to a user perspective.

**Rangatiratanga vs. public health objectives**

In *He Korowai Oranga*, *rangatiratanga* (‘self-determination’) is conceptualised as a process whereby Māori aspirations determine the shape and direction of their own institutions, communities and development (Ministry of Health 2002a:5). While rangatiratanga has generally been applied to leaders of iwi and the collective they represent, the idea is utilised at the individual level for the purposes of this analysis.

Participants (and whanau) are viewed as holding autonomous and independent health objectives, which may not necessarily differ from those held by their case managers. Consultation with participants regarding treatment decisions acknowledges the mana (‘integrity’, ‘authority’) and right of the individual to control what happens to their bodies. In the consultative process this means that participant input is recognised and responded to by their partners - the case managers.

However, medical responses to notifiable infectious diseases such as TB have multiple imperatives driving treatment decisions. Aside from the treatment of the individual, there is also the fundamental issue of protecting the population from perceived public health threats. To encourage reluctant individuals to complete treatment, incentives or contracts may be used. However, if a person adamantly refuses treatment whilst infectious, a court order to detain and isolate that person can be sought (Ministry of Health 1996:1). Kowhai initially refused to return to hospital for treatment, having left while still infectious.

I got threatened by [PHN]. Well it wasn’t a threat it was just the truth. Um, I didn’t want to be locked up in hospital, I didn’t want to have to stay in one room all day for a year…and it scared me, cos it meant I didn’t get any visitors, my partner couldn’t be there next to me…” (Kowhai, aged 24yrs).

While Kowhai’s experience is not common, as threatening to detain individuals is rare (Thornley, personal communication 2005), her experience shows that patient choice can be curtailed if public health authorities deem it to be in the interest of public health. Another participant initially resisted her TB treatment because of adverse side-affects from one medication; eventually another drug was prescribed. Generally though, most participants cooperated with their case managers, believing they had relatively little control and few choices because they had TB.

This analysis of the principle of partnership in application to TB, highlights the constraints around some attributes of partnership when dealing with a notifiable disease. In particular, patient choice, effective communication and, in some instances, a duty of care are significant challenges.

**Principle of Participation**

The focus of this principle is to facilitate the development of processes that increase Māori participation in all areas of New Zealand society (Royal Commission on Social Policy
He Korowai Oranga aims to target health inequalities which contribute to low levels of health service usage by Māori.

Access to healthcare is defined by Andersen et al. (2001:3) as “actual use and everything that facilitates or impedes use”. These include demographic factors (income, education and employment), knowledge of services and their function, proximity to those services and cultural beliefs around health and illness (Andersen et al. 2001:3-30). The Geneva Declaration on the Health and Survival of Indigenous Peoples also includes the consequences of colonisation (United Nations Economic and Social Council 2002).

He Korowai Oranga anticipates that addressing these factors will enable Māori to access health services (Ministry of Health 2002a). However, whilst policy mechanisms can mediate some of the structural and economic barriers to accessing clinical treatment, negotiating the stigma surrounding infectious diseases like TB is much more difficult.

**Stigma**

Goffman (1963) describes stigma as anything that publicly discredits us. Such things threaten our presentation of self and are often morally discrediting too. Unsurprisingly, individuals with TB follow the behavioural patterns outlined by Goffman, strategising in order to manage the circulation of potentially damaging information by carefully concealing or strategically disclosing their diagnosis (Goffman 1963:41-51). The amount of social stigma experienced by individuals can influence treatment adherence or even abandonment of TB treatment (Rubel & Garro 1992:631-2).

In this study, all participants indicated they were aware of stigma associated with having TB. Stigma was perceived in all of the different environments – whānau social, working, community, and health, within which participants operated.

For half the participants in this study, TB fractured or strained whānau relationships.

… my own brother…I went back one time and he said to me don't touch my kids, you know, you might have TB. I said but I've been tested, you know, and then he started saying to me, oh, well Kowhai’s got TB. So you must have TB, don't touch my kids. And that really bumm diced me out… (Rau, Kowhai’s partner).

Rau’s story illustrates how, whānau continue to be fearful of TB even though there may be no imminent threat of infection. Another participant only discovered his partner was the probable source of his TB, after the PHN advised him. He explains his partner’s reluctance,

Well she’s funny medical wise. She keeps things to herself; you know… she keeps it under wraps. She’s arr, a bit reluctant to let anyone know, that she, her family's got it… Arr she'll think, ooh, they know I got TB. They'll, you know, they'll think oh keep away from that lot (Hemi, aged 57yrs).

For another participant there were changes in her interactions with colleagues after returning to work”

I felt, that people were staying clear of me…it was like danger, stay away…[So no hongi?]…no coming in, no, no, you know, cos we always kissed (Omaka, aged 62yrs).

Generally, participants found that there were only subtle changes in their social contacts:

… just the funny looks that I got. I mean, they'd still share a cigarette. It’s just the looks I got, but they'd still share the cigarette (Kowhai, aged 24yrs).
Six participants believed they had experienced different health treatment because of their TB illness, from non-medical hospital staff, nurses, doctors, auxiliary health support services and general practitioners. The other four did not. For two participants who had fully recovered from TB, subsequent hospital admissions appeared to be strongly influenced by their TB history:

...so like every time he goes into hospital now...attitudes change as soon as they find out he's had TB, he goes straight into isolation (Manaia, partner of Hone, aged 54yrs).

...right across my file, TB...so of course, straight into isolation...and on the outside of the door, TB...(Omaka, aged 62yrs).

While the actions of some medical professionals highlight the need for more sensitive and discreet management of TB patients, in some instances whānau were a more significant source of stigma for participants in this study.

Access or ‘Getting to clinic’

Most participants relied on the intervention or support of another person to get to the three monthly clinical appointments at either Greenlane or North Shore Hospital. The Public Health Service closely monitors attendance at clinical appointments, with any missed visits promptly investigated by a PHN. Non-attendance is considered to be an indication that a patient requires closer supervision or more support getting to clinical appointments (McLean 2003:1-17, ARPHS 2003:5-8).

Participants in this study used a variety of resources and strategies to overcome transport barriers to attending outpatient appointments. For half the participants, all living in outer Auckland suburbs or in rural communities, there was a considerable geographical distance from home to hospital. Of those living in rural communities, three did not own vehicles or hold a current drivers’ licence and public transport was not a practical option as services to rural areas are often limited or unavailable. Of the six participants who held a valid licence, four owned a vehicle, although one car was unregistered and without a warrant of fitness.

Car-less participants used various resources to get to their clinical appointments. One rural participant hitchhiked to work each day and had attempted, unsuccessfully, to hitchhike to his clinical appointments ninety kilometres away. An urban participant used volunteer driver services, whilst other participants were able to rely on whānau to transport them to appointments. Six relied heavily on PHNs and the resources of the Auckland Regional Public Health Service (ARPHS) to attend TB clinics and other treatments.

Somehow we really make sure they get to those appointments. We make sure we're there...We either pay for that via the service, like taxi chits, or, um petrol vouchers. For the person who may or may not be, maybe taking them in, or we pick them up ourselves.

(Marama, Public Health Nurse).

While this result reflects the policy objectives of He Korowai Oranga, anecdotal evidence suggests that smaller public health services in other regions have considerably less resources with which to support patient access to clinical services (PHN, personal communication).

The principle of participation highlights the factors which influence access to TB treatment. The principle also brings into sharp relief the pervasiveness of stigma around TB and the difficulty of combating the existence of stigma within whānau. In this study historical experience with TB, misinformation and fear of infectiousness appeared to be the main causes of stigmatising responses.
Principle of Protection

The offer of protection featured prominently throughout the Preamble to and content of the Treaty of Waitangi. Historically the principle of protection has been limited to intermittently upholding Māori property rights (Waitangi Tribunal 2001:54). Not until the 1987 case of New Zealand Māori Council vs. Attorney General, was the extent of the Crown’s responsibility for protecting Māori interests clearly outlined.

The Court of Appeal held that the Crown’s duty was not passive, and extended to active measures of protection. Such a responsibility was akin to a fiduciary duty where one party had an obligation to protect the interests of the other party as the more powerful in the agreement (New Zealand Court of Appeal 1987). In exploring Crown responsibility, the Waitangi Tribunal has increasingly placed emphasis on the need to protect intangible assets.

A strong cultural identity is an important contributor to people’s wellbeing, positively correlating with good health, even in the presence of adverse socio-economic conditions (Durie 2001:35-60, Aggett 1996). A key strategy of He Korowai Oranga is the safeguarding of Māori culture, beliefs and values through the reorientation of health services which serve Māori, to service provision from a Māori perspective of health and wellness (Ministry of Health 2002a).

Taonga

An accepted translation of taonga is ‘treasures’ or ‘anything highly prized’ (Kawharu 1989:320-1). Māori consider intangible valuables taonga too. Language, cultural knowledge and the mauri (‘life principle’) of a river are some examples. The Courts have ruled that preservation of taonga does not lie solely with the Crown. Māori as Treaty partners must share in that responsibility (Te Puni Kokiri 2001a:60-61).

In this study, nearly all participants valued their Māori identity. Expressions of Māori identity by older participants appeared to be shaped by the degree of contact with their marae (‘meeting area’ or ‘focal point’), proficiency in te reo (‘Māori language’) and childhood grounding in tikanga (‘Māori cultural protocols’). While younger participants also identified strongly as Māori, their conceptions of Māori identity appeared to mediate traditional expressions of being Māori with contemporary material, geographical and social influences (McIntosh 2005:46).

I only know the basics. I think that's all I probably will learn to do...I'm like Māori hard but not in the language. Not even in Māori culture. I don't think I would adapt to it very good...(Pania, mother of Mahina, aged 22mths)

The ability of policy such as He Korowai Oranga to respond to cultural differences within a group appears to depend not only on the knowledge, perceptions and responses of health professionals, but also on individual health practices, cultural beliefs and values in relation to being Māori.

Active protection

Active protection refers to the duty of the Crown to take proactive measures to protect Māori interests (Court of Appeal 1987). Here, Māori interests are defined as Māori health, culture, values and beliefs. Proactive measures in the treatment of TB include health-promoting
strategies, acknowledging different cultural health models and enhancing participant knowledge of TB disease and treatment (Ministry of Health 2002b).

Participant knowledge of TB disease and treatment indicates that Auckland Regional Public Health Service strategies to inform participants about TB are effective. Informing patients and whanau about TB can support individual health-keeping strategies - an important component in safeguarding individual wellbeing, public health and containment of TB disease. Most participants did understand TB was infectious and described measures and strategies to prevent infection spreading to others.

In circumstances where stigma is an obstacle to providing effective treatment, a hui (‘meeting’) may be called, with all whanau members invited to be involved. Māori elders, key health providers and medical professionals attend, explaining their experiences and their role, in order to provide information to whanau about TB disease and treatment:

... when I have called the hui of the family it’s very interesting, because when you get um, the older family members in the room. Or in a bigger hui, like kaumatua [‘male elder’] and kuia [‘female elder’] they, they always remember TB from the ‘50s’ and what it did to their families. And so I find my job is, is a lot easier. Because they get up and they talk about it...they start to see it from a different light...I just think that it helps, a lot (Marama, Public Health Nurse).

The use of hui to disseminate information through informal networks is a strategy used in smaller rural communities and is an example of effective use of community resources to distribute critical health and disease information. It also highlights the advantage of engaging with some Māori communities in local culturally appropriate ways, and is the basis upon which partnerships as outlined in He Korowai Oranga can be formed.

In summary the principle of protection highlights the importance of engaging health service users with their treatment in ways that are meaningful to the user. From this study, diverse approaches with which to develop effective health care services for Māori with TB, are evident. However, the range of ways participants expressed their Māori identity indicates that such strategies will need to move with such understandings if health treatment is to remain effective for all Māori.

Conclusions

Māori with TB have a long and complicated relationship with the health care services, services which have not always been shaped around Māori health needs. He Korowai Oranga is an attempt to do that but some parts of the health services are still struggling to fulfil that expectation.

The principle of partnership highlights the challenges to TB patient expectations – particularly in relation to informed consent and how rigorously the concept or partnership is engaged with by some health professionals. The imperative to protect public health does have the potential to override individual choice in the TB treatment process.

The principle of participation illuminates the limitations of policy to negotiate less tangible barriers to accessing healthcare. While economic and geographical constraints can be mediated through the support of health professionals and regional health services, results from this study indicate the impact of stigma on Māori TB patients’ remains a most potent obstacle.
In line with generally accepted interpretations of the principle of protection, *He Korowai Oranga* affirms Māori identity, culture and beliefs. However, effective policy development depends on reliable information based on actual experiences of Māori (Te ropu rangahau hauora a Eru Pomare 2000, Kukutai 2004). A key challenge to the effectiveness of *He Korowai Oranga* may be whether the definitions of Māori referenced are reflective of the lived reality and diversity of contemporary Māori.

The referencing of Treaty principles in health care services for Māori, while not yet a perfect fit, provides an opportunity to deliver positive health outcomes. Shaping health services toward Māori understandings of health and wellness may well prove to be the strategy needed to bring down current rates of TB amongst Māori.

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Despite efforts to control tuberculosis (TB), this infectious disease continues to be identified as a serious global public health concern in part due to the emergence of multiple and extreme drug resistant strains of TB and co-infection with HIV/AIDS. Despite the fact that TB is preventable and treatable, it is estimated that one-third of the world’s population is infected with latent TB (Dye et al. 1999) and that each year more than eight million new cases arise and almost two million people die as a result of this communicable disease (Dye and Floyd 2006). The highest rates of TB are found in developing nations where poverty, crowding and insufficient health care programs are prevalent.

In Canada and other developed countries, TB rates have fallen dramatically since the beginning of the 20th century. These significant declines have been achieved with a combination of improved living standards, public health interventions and more effective drug treatment (PHAC n.d.). Yet, despite the fact that Canada is fortunate enough to now have one of the lowest rates of TB globally, (5.0/100,000 pop/year), more than 1600 new cases of TB arise each year (PHAC 2007a) and of those reported cases, approximately 11 percent are resistant to one or more TB drugs (PHAC 2007b). Moreover, although TB is no longer considered a major cause of disease in Canada for the general population, it has been recognized that there are pockets of the Canadian population that are at increased risk of infection (Cairney 1996). These include: individuals born in or travelling to countries where TB is common; people who are of Aboriginal descent; people who are homeless or under-housed; people suffering from alcoholism; IV drug users; people with HIV infection or AIDS; residents of long-term care institutions (nursing homes and correctional facilities); people with high risk medical conditions (e.g., chronic renal failure, transplantation, silicosis, carcinoma of head and neck, and diabetes); people aged 65 years or older; and staff/volunteers who work with any of these high risk groups (PHAC 2004b, Ontario Lung Association 2003:4). Of these groups, foreign-born individuals from TB endemic areas who arrived in Canada within the past 5 years and Canadian-born, Aboriginal peoples account for the highest proportion of TB cases in Canada (Canadian Lung Association 2000).

Aboriginal peoples1 have been at increased risk for TB since their early contact with Europeans (Health Canada 1999). The introduction of the reserve system facilitated the spread of infectious agents such as TB, measles and influenza, resulting in exceedingly high mortality rates (Enarson 1998, Waldram et al. 2006). The TB epidemic in the Aboriginal population began in the late 19th century, and reached its peak during the early 20th century. It did not come under some semblance of control until the 1960s (Young 1998:S24) ensuing rates of TB in the Aboriginal population remained considerably high compared to rates experienced in the general population (Wherret 1965, Enarson 1998). Despite early interventions and the later introduction of the National Tuberculosis Elimination Strategy for Aboriginal Peoples of Canada in 1992, Canadian-born Aboriginal peoples still have TB rates that are more than five times higher than the national average (PHAC 2006a). These higher than average rates have been attributed to such factors as poverty, malnutrition, crowding and limited access to health care and clearly reflect the larger socio-cultural, historic, political and
economic context within which Canadian Aboriginal people reside. Without more effective interventions including socio-economic solutions, it is thought that TB will continue to remain a significant problem in the Aboriginal population for the foreseeable future (FitzGerald et al. 2000).

This chapter will: (1) demonstrate that TB is a continued threat to the health of the Aboriginal population in Canada; (2) discuss the nature and scope of TB information currently available on Aboriginal Canadians; and (3) highlight the need for more appropriate approaches to studying and managing TB in the Aboriginal population. It will be argued that an improved understanding of the persistence of TB in Aboriginal communities may reside with participatory community-based approaches that integrate biomedical, indigenous and social science knowledge.

Tuberculosis in Aboriginal peoples: past and present

Although TB existed in the Americas prior to European contact (Salo et al. 1994, Arriaz et al. 1995), as Ferguson (1955:60) points out, it was not believed to be, “a scourge among the Indians, and it was not a major cause of death until after they had settled on the reserves in the 1880s”. Following contact with Europeans, Aboriginal people experienced higher infection and lower survival rates of TB than their non-Aboriginal counterparts (for a more in-depth commentary on the effects of European contact on disease in Indigenous Canadian populations please refer to Waldram et al. 2006). This was often incorrectly attributed to Aboriginal people having a “special susceptibility to tuberculosis because they lacked ‘racial immunity’” (McCarthy 1912: 207 cited in Waldram et al. 2006:69). Hodgson (1982:503) suggests rather, that the following conditions facilitated the devastatingly rapid spread of TB throughout many Aboriginal communities: “…the lack of previous exposure to the disease, malnutrition and/or changes to the diet, a shift from semi-nomadic to a sedentary lifestyle, overcrowding in governmental housing and schools, increased and prolonged contact with non-natives, debilitation by other diseases and epidemics, poor sanitation, lack of medical care, alcoholism, and cultural and psychological anomie.” Under these particular conditions, TB flourished and rapidly spread through communities. A case in point involves the Cree in the Qu’Appelle Valley region of Saskatchewan, who began to settle on reserves in 1881. From 1881 to 1886, the TB mortality rate of these Aboriginal people rose from approximately 1000 per 100,000 to 9000 per 100,000 (Ferguson 1955).

By the 20th century TB was considered a serious health problem in Canadian Aboriginal peoples, not only as a specific cause of death, but also as an important factor in increasing vulnerability to other infectious diseases (Stone 1926 cited in Waldram et al. 2006). During the early decades of the 20th century, the mortality rate from TB in the Canadian Aboriginal population was as high as 700 per 100, 000. In Aboriginal children aged zero to four years, mortality rates from TB meningitis ranged from 500 to 2000 per 100,000 while overall TB death rates during the 1930s and 1940s among children in residential schools reached as high as 8000 per 100,000 (Wherret 1977, Health Canada 2006). A combination of factors such as malnutrition, confinement on crowded reserves, and lack of immunity to the TB bacillus contributed significantly to the epidemic (Wherret 1977, Grzybowski et al. 1976). Prior to the 1940s, the federal government took little, if any, responsibility for the high mortality and morbidity rates found within Aboriginal communities. However, in time the threat of disease posed by this minority to the majority could no longer be ignored, and a stringent campaign arose against this ‘center of contagion’. At that time, the government’s solution to the TB
problem in Aboriginal communities was to evacuate and institutionalise the sick. Consequently, Aboriginal peoples infected with TB were forced to exist in a very different cultural and social milieu, isolated from the support of family and friends (Hodgson 1982). As a result of this experience, there exists a long-lived fear of institutions and widespread mistrust and resentment of non-Aboriginal health care professionals (Jenkins 1977).

The introduction of effective chemotherapy resulted in a drastic and steady decline in Aboriginal TB rates throughout the 1950s, 1960s and 1970s, and was followed by a leveling off in the 1980s (Clark and Riben 1999). However, in the 1990s the rates of TB in this population began to increase once again. In 1992, in recognition of this increase, the Medical Services Branch of Health Canada (now First Nations and Inuit Health Branch) introduced the National Tuberculosis Elimination Strategy for Aboriginal Peoples of Canada. This strategy focused on immunisation, diagnosis, contact tracing, education and research. The goal of the strategy was to reduce the incidence of TB in First Nations to a rate of 1 per 100,000 by 2010 (Health Canada 1999). Yet despite the existence of TB treatment and prevention options and the introduction of the Elimination Strategy, Canadian Aboriginal peoples remain at increased risk for activation and re-activation of TB (MacMillan et al. 1996). In 2005 Canadian Aboriginal peoples experienced TB rates approximately 30 times higher (26.8/100,000) than the Canadian-born, non-Aboriginal population (0.9/100,000) and almost twice as high as the foreign-born population (14.8/100,000) (PHAC 2006a). Figure 1 illustrates that while TB rates leveled off or decreased from 1992 to 2005 in the Canadian-born, non-Aboriginal population and the foreign-born population, respectively, the Aboriginal population has recently experienced an increase in rates.

**Figure 1** Canadian tuberculosis rates by origin, 1992-2005.
It should be noted, however, that the above-mentioned rates for Aboriginal peoples (as well as the other subpopulations) reflect the overall Canadian average for this population thereby masking regional variability. Table 1 shows that provincial and territorial rates per 100,000 for Aboriginal peoples are consistently higher in Saskatchewan, Manitoba, and the North\(^3\) than rates recorded for the remaining provinces, indicating the problem is even more serious in these geographic regions. Moreover, the category titled the “North”, which includes the Yukon, the Northwest Territories and Nunavut, conceals the fact that TB rates vary in these three areas (CBC June 2, 2006). Table 1 also reveals the significant variability in provincial rates that occur from year to year. For example, in 1999 Aboriginal peoples in Alberta and Saskatchewan experienced rates of 21.8 and 83.3 respectively, while in 2003 rates of 10.8 and 56.6 were recorded.

Table 1  Tuberculosis rates per 100,000 for Canadian-born Aboriginal peoples – Canada and provinces/territories, 1999-2003.

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<tr>
<td>Newfoundland and Labrador</td>
<td>4.9</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>4.9</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>6.4</td>
<td>1.6</td>
<td>10.9</td>
<td>10.4</td>
<td>--</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>--</td>
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<tr>
<td>New Brunswick</td>
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</tr>
<tr>
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<td>6.2</td>
<td>6.1</td>
<td>5.8</td>
<td>4.0</td>
</tr>
<tr>
<td>Ontario</td>
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<td>3.8</td>
<td>6.3</td>
<td>6.5</td>
<td>3.6</td>
</tr>
<tr>
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<td>28.9</td>
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<td>30.0</td>
<td>53.0</td>
</tr>
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<td>Saskatchewan</td>
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<td>56.6</td>
</tr>
<tr>
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<td>13.8</td>
<td>12.8</td>
<td>10.8</td>
</tr>
<tr>
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<td>14.6</td>
<td>20.7</td>
<td>20.5</td>
<td>14.0</td>
</tr>
<tr>
<td>North(^3)</td>
<td>70.0</td>
<td>109.3</td>
<td>83.6</td>
<td>58.3</td>
<td>35.2</td>
</tr>
</tbody>
</table>


In addition to provincial differences, TB outbreaks and epidemics vary by Treaty areas and First Nations communities. In Alberta in 2004, 67 percent of all First Nations active TB cases came from one Treaty Zone (Alberta Health and Wellness 2007) and in Ontario, between 1996 and 1999, 76 percent of all TB cases in First Nations were attributable to five communities within one Treaty zone (Health Canada 1999). First Nations communities found to be at highest risk for TB outbreaks and hyperendemicity are those which are remote, those with health care worker shortages, communities implementing new health transfer agreements, and those with poor housing conditions and crowding (Health Canada 1999).

One recent community example involves the Garden Hill First Nation in Manitoba who garnered national attention in the spring of 2006 when it was reported that 17 new cases of TB had been reported within a month for a total of 19 new cases in the community (CBC April 13, 2006). The local nursing station failed to diagnose cases; instead residents sought physician treatment in Winnipeg (600 kilometres south) resulting in a delay in treatment and exposure of other community members. The Chief of the First Nation reported that health
officials advised community members to wash their hands after sneezing to prevent the spread of infection. The Chief went on to note that many of the residents are “living in third world conditions” and “the majority of the homes in Garden Hill don’t have running water” (CBC April 13, 2006). This crisis, along with the death of a six year old Aboriginal child from TB in another community the following month, prompted National Chief Phil Fontaine to say “We’ll never eradicate TB in First Nations until we eradicate poverty” (CBC May 18, 2006).

The incidence of TB in the Aboriginal population has also been shown to vary inversely with the time interval of contact with European settlers (e.g., higher rates occurring in areas last exposed) (Enarson 2001, Waldram et al. 2006). Table 2 reveals that Aboriginal TB cases make up 95 percent of the cases in the North3, 90 percent in Saskatchewan and almost 70 percent of all cases in Manitoba. This table also highlights the fact that, although Aboriginal people in Canada only make up 3.3 percent of the total Canadian population (based on the 2001 census), they accounted for 15.2 percent of all TB cases in Canada in 2003.

Table 2 Percentage of tuberculosis cases in Canada by origin – provinces/territories: 2003.

<table>
<thead>
<tr>
<th>Geographic Region</th>
<th>Canadian-born non-Aboriginal</th>
<th>Canadian-born Aboriginal</th>
<th>Foreign-born</th>
<th>Unknown birthplace</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>16.4</td>
<td>17.3</td>
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<tr>
<td>British Columbia</td>
<td>12.1</td>
<td>8.5</td>
<td>75.1</td>
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<td>14.2</td>
<td>69.3</td>
<td>16.5</td>
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<td>New Brunswick</td>
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<td>0.0</td>
<td>16.7</td>
<td>16.7</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>50.0</td>
<td>16.7</td>
<td>16.7</td>
<td>16.7</td>
</tr>
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<td>66.7</td>
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<td>0.0</td>
</tr>
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<td>7.8</td>
<td>1.2</td>
<td>88.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Prince Edward Island</td>
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<td>66.7</td>
<td>0.0</td>
</tr>
<tr>
<td>Quebec</td>
<td>31.8</td>
<td>1.6</td>
<td>65.1</td>
<td>1.6</td>
</tr>
<tr>
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</tr>
<tr>
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<td>0.0</td>
<td>95.0</td>
<td>5.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Canada</td>
<td>14.1</td>
<td>15.2</td>
<td>68.2</td>
<td>2.5</td>
</tr>
</tbody>
</table>

(PhAC 2007a:19)

Aboriginal peoples’ over-representation in the Canadian TB statistics is the result of the perpetuation of many negative conditions and circumstances stemming from colonial experiences and relationships with the Canadian government. Inequities in the health status of Aboriginal peoples in Canada in general are linked to a complex interplay of social determinants and circumstances rooted in generations of colonial policies which sought to undermine their culture. It is recognized that factors related to colonialism remain a significant determinant of health for Aboriginal peoples in Canada (PhAC 2004c), and that mechanisms of colonialism have changed in Canada but have not ended (Aboriginal Healing Foundation 2005, Fleras and Elliot 1992). Improving health and healing for Aboriginal peoples is increasingly linked to empowerment and self-determination coupled with improved relations with the dominant society. This includes the need for Canadian citizens to learn and acknowledge the history of
relations between Aboriginal peoples and Canada and to end mainstream indifference to Aboriginal issues (Warry 2007). As it stands, Aboriginal people in Canada are disproportionately affected by many social, economic and behavioural risk factors such as poverty, homelessness, overcrowding, limited access to, or use of, health care services, poor nutrition, alcoholism and drug abuse which individually and in concert increase their vulnerability to many illnesses including TB (Clark et al. 2002, Clark and Riben 1999, Muir 1991, Shkilynk 1985). As well, they have a higher than average prevalence of medical risk factors for TB, such as diabetes, cancer, and renal failure (Muir 1992; PHAC 2006c). Aboriginal peoples are also at increased risk of being affected by the AIDS epidemic given the above mentioned factors and their high rates of sexually transmitted diseases (PHAC 2006c). A steady increase in the proportion of AIDS cases and positive HIV test reports among Aboriginal peoples in Canada have been recorded over the last few years (PHAC 2006c). If the number of HIV and AIDS cases continues to rise in the Aboriginal population, it follows that the TB-HIV interface will present a new major health problem for Aboriginal peoples.

**The focus of the tuberculosis literature**

It has been established thus far that TB continues to plague the Canadian Aboriginal population in an era in which biomedical interventions are readily available. Transmission is being aided by crowded living conditions, TB infection and disease is being facilitated by underlying medical conditions as well as drug and alcohol abuse which acts to weaken the immune system, and re-activation is occurring due to social and economic stresses associated with Aboriginal peoples’ place in both historical and contemporary Canadian society. Further, TB appears to be highly variable between regions and communities. Consequently, it seems to follow that solutions to the problem must lie in research efforts that endeavour to address the social, economic and political situation faced by Aboriginal communities rather than biomedical studies that focus exclusively on clinical and epidemiological aspects of the disease at the population level.

**Methods**

In order to determine the nature and scope of peer reviewed articles published on TB with a principal focus on the Canadian Aboriginal population, a number of database queries were conducted. MEDLINE was searched for the 50 year period from 1957 to 2006. To confirm that the results obtained from MEDLINE were not biased as a result of using a biomedical database, searches were also performed on the following social science databases accessed through Scholars Portal: Applied Social Science Index and Abstracts (1987-Current); Bibliography of Native North Americans (1950-Current); International Bibliography of the Social Sciences (1951-Current); Social Sciences Abstracts (1984-Current); and Social Sciences Citation Index (1976-Current). The following key word combinations were used: “tuberculosis” combined with “Canada” and a combination of the following names for Aboriginal groups: “Native”, “Indian”, “Aboriginal”, “Indigenous”, “Eskimo”, “Inuit” and “First Nations”. The Native Health Research Database was also examined using the key word “tuberculosis”. Each abstract was reviewed to determine if the study encompassed a biomedical or social determinants framework to study TB. If the abstract was unavailable, the actual paper was reviewed. Although each database is unique in its organization of material and the results are not directly analogous (e.g., date distinctions), the trends revealed during these searches were compared.
**Results**

The MEDLINE search generated 79 citations. Of these citations, 13 were immediately eliminated because they did not focus on Canada, Aboriginal peoples or tuberculosis. A further three were removed because they were commentaries on other articles. An additional 22 of the remaining articles were also eliminated because while they briefly mentioned Aboriginal peoples and TB, this population was not the primary focus of the paper. These articles tended to concentrate more generally on high risk groups associated with TB (e.g., immigrants, poor inner-city residents, prison populations, school children, pediatric cases and HIV-positive individuals). Oftentimes, Aboriginal peoples were only mentioned in so much as their TB rates were used as a comparison to the group under study. Table 3 reveals that of the 41 remaining articles, 28 fall principally within the biomedical realm while only 13 consider and discuss the role that socio-economic, cultural, political, and/or historical factors play in the transmission and perpetuation of TB in the Canadian Aboriginal population.

The Scholars Portal search generated 20 peer reviewed citations. When duplicates were removed, only ten citations remained. Of those citations, four were eliminated because they did not focus on Canada, tuberculosis specifically or fell beyond the date restriction (e.g., 2007 publication). Table 3 shows that of the remaining six articles, four fall within the biomedical area and two within the social determinants framework. It should be noted, that all six articles, with the exception of one that focused on the paleopathology of TB in an Iroquoian ossuary, were also retrieved in the MEDLINE search.

A search of the Native Health Research Database produced 102 peer reviewed citations, spanning the years 1970 to 2006. When the articles focusing on the American Indian/Native American population were removed, 26 Canadian-focused articles remained. Of those citations, 14 were removed because they did not focus specifically on Aboriginal peoples or tuberculosis. Of the remaining 12 articles, only one article considered the role of history, socio-economic conditions and the cultural characteristics of the Aboriginal people, especially their healing models and language. The other 11 articles, many of which were also retrieved in the MEDLINE search, concentrated primarily on the epidemiological, molecular and clinical characteristics of TB in Aboriginal peoples in Canada (refer to Table 3). Table 3 clearly displays the considerable overlap in the articles identified in MEDLINE, Scholars Portal social science databases and the Native Health Research database.

### Table 3  Database Search Citations

<table>
<thead>
<tr>
<th>Citations</th>
<th>Database</th>
<th>TB Research Focus</th>
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<tr>
<td></td>
<td>MEDLINE</td>
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</tr>
<tr>
<td>Moore 1964</td>
<td>X</td>
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</tr>
<tr>
<td>Carey 1965</td>
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<td></td>
</tr>
<tr>
<td>Herbert &amp; Burchak 1967</td>
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</tr>
<tr>
<td>Jeanes et al. 1972</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Wilson et al. 1973</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Mankiewicz &amp; Liivak 1975</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Hodgson 1982</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
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<td>-------------------------------</td>
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<tr>
<td>Narain 1982</td>
<td></td>
<td></td>
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<tr>
<td>Trevenen &amp; Pagtakhan 1982</td>
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<td>Grzybowski &amp; Dorken 1983</td>
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<td>Dorken et al. 1984</td>
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<tr>
<td>Pfeiffer 1984</td>
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<tr>
<td>Young 1985</td>
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<tr>
<td>Enarson &amp; Grzybowski 1986</td>
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<td>Young &amp; Hershfield 1986</td>
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<tr>
<td>Young &amp; Casson 1988</td>
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<td>Jakubowski et al. 1988</td>
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<td>Wobeser et al. 1989</td>
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<td>Houston et al. 1990</td>
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<td>McGrath 1991</td>
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<tr>
<td>Young &amp; Mirdad 1992</td>
<td></td>
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<tr>
<td>Rideout &amp; Menzies 1994</td>
<td></td>
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<tr>
<td>Young 1998</td>
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<td>McGillivray et al. 1998</td>
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<td>Wang et al. 2000</td>
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<td>Hoeppner &amp; Marciniuk 2000</td>
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<tr>
<td>Kunimoto et al. 2001</td>
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<td>Clark et al. 2002</td>
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<td>Cook et al 2004</td>
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Figure 2 highlights the total number of citations (n=45) identified from the database searches with all duplicates removed. Figure 2 confirms the overwhelming biomedical focus identified in all three searches, even the social sciences databases accessed through Scholars Portal and the Native Health Research database, and draws attention to the decreasing trend in Canadian Aboriginal TB articles from 1982 to 1996 and an increasing trend from 1997 to 2006.

**Figure 2**  Database (MEDLINE, Scholars Portal, Native Health) search results, 1957-2006.

**Discussion**

Although TB is recognised as a disease rooted in the social conditions of communities, the results of the database searches reveal that the majority of literature available on TB in Canadian Aboriginal peoples comes from clinical and epidemiological studies. The focus of many of the articles was the bacilli Calmette-Guerin (BCG) vaccine and the health implications associated with its use on Aboriginal infants, the effectiveness of mass neonatal BCG vaccination campaigns, the general effectiveness of the vaccine and the relationship between BCG and tuberculin sensitivity. A number of the articles concentrated on molecular epidemiology, in particular on the usefulness of DNA fingerprinting in determining transmission patterns in
communities. Other studies focused on: incidence and prevalence rates; compliance rates; treatment plans; clinical trials of TB medication; tuberculin skin tests; the clinical manifestations of certain types of TB; and TB control efforts. Although the majority of research continues to concentrate on biomedical studies, we note an overall increase in the number of publications focusing on TB in Aboriginal peoples over the past 15 years.

The database searches revealed a much lower number of articles with a focus on the social determinants of TB. Comparatively, little attempt has been made to conduct studies that endeavour to explore and address the social mechanisms responsible for TB in the Aboriginal population. Those articles identified as contributing to a more social understanding of TB concentrated on issues such as: the association between housing density, isolation and TB; the socio-cultural factors influencing prevention and treatment efforts; the importance of enlisting community members’ and health care workers’ support in TB control strategies; factors affecting compliance with preventative treatment; and the social, political and historical factors that shape Aboriginal perspectives on TB. Some articles had a primarily historical focus. A few papers highlighted the role of colonial practices and the resulting ecological, economic and political changes that created conditions that facilitated the transmission of TB in Aboriginal populations/communities. Another examined how Aboriginal children of the Qu’Appelle reserves in southern Saskatchewan became the subjects of a trial of the BCG vaccine in 1933. Finally, one paper looked specifically at Inuit explanatory models of health and TB in the 20th century.

Integrated approaches to studying TB in Canadian Aboriginal communities

While we are aware that biomedical studies on TB are necessary, given our long-standing knowledge of the social mechanisms of TB epidemics it is surprising to find that the predominance of research continues to occur within the biomedical realm. Despite the existence of therapies to prevent and treat TB, this disease remains a significant public health problem for Aboriginal peoples. In Canada, medical strategies have been successful in substantially reducing morbidity and mortality from TB in the general Canadian population. However, these efforts have proven less successful in the Aboriginal population where infection rates are five times higher than the national average. Clearly biomedical interventions alone are not the answer to a disease that is deeply rooted in the social circumstances of communities. Nevertheless, this review of the literature shows few attempts in recent years to understand the underlying societal mechanisms responsible for maintaining TB at such high rates in this population.

Since medical risks exist for TB in Aboriginal peoples (e.g., diabetes, HIV/AIDS, cancer), as well as social risks and vulnerabilities (e.g., crowding, poor nutrition, substance abuse), integrated research strategies and intervention models are necessary. As Dubos and Dubos (1992) state:

Tuberculosis is a social disease, and presents problems that transcend the conventional medical approach…its understanding demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body (cited in Farmer 1997:348).

Yet, although the importance of the social and economic environment in the transmission and persistence of TB has been noted (CDC 1995, Farmer 1997, 1996), the emphasis is still on clinical and epidemiological research. FitzGerald et al. (2000:351) believe that “A reduction
in rates will likely be achieved only with improvements in socioeconomic status and community involvement in disease management combined with comprehensive medical surveillance and treatment programs”.

Participatory and interdisciplinary research that seeks to bring together indigenous, biomedical and social science knowledge concerning TB is the direction that researchers should take if they hope to improve our understanding of TB and improve research relationships with Aboriginal peoples. For more than a decade researchers have come under increased criticism for the production of knowledge concerning Aboriginal peoples that is sometimes damaging to their culture and community and often of little use in improving health (CIHR 2006). Increasingly Aboriginal people, communities and leadership are insisting on research for action. They are asking to be involved in research and to inform, direct and participate in the research process so that local and appropriate solutions can be discovered (RCAP 1996). Consequently, the study of TB requires a more community-based approach that incorporates biomedical and social determinants as well as community knowledge, beliefs and values in order to decrease rates of TB in Aboriginal peoples.

Conclusions

TB is a disease that is not distributed evenly among Canadians. It has been shown to disproportionately affect the poorest, most marginalized and vulnerable groups in our society. Aboriginal peoples are at increased risk because of their present socio-economic conditions (Health Canada 1999) and because limited progress has been made towards de-colonization and self-determination (Aboriginal Healing Foundation 2005, Fleras and Elliot 1992). Only modest improvements in conditions for Aboriginal people in Canada have been seen in recent times.

Research has shown that there is a lack of social determinants research being conducted on TB in Canadian Aboriginal populations. With rates of TB in Aboriginal peoples much higher than the national rate, and increasing, there is a need for research within this realm. The epidemiological and clinical literature is available; what is lacking is the knowledge of which communities are vulnerable to TB and a comprehensive understanding of why these communities are still at risk of TB infection and disease. Because TB is a social disease, our understanding can only be advanced by researchers who attempt to integrate community level socio-economic, historic and political factors with biomedical data. The collection and subsequent availability of Aboriginal community level data may ultimately allow for the creation and implementation of culturally appropriate and effective TB prevention and intervention strategies, which may finally reduce or possibly eradicate the presence of TB in the Canadian Aboriginal population.
References


**Notes**

1 “Aboriginal peoples” refers collectively to the descendents of all of the original inhabitants of Canada.

2 Rates for 2005 are provisional until publication of the Tuberculosis in Canada – 2005 Annual Report.

3 The North includes the Northern Territories, Nunavut and the Yukon.
Part 2 Reproducing Tuberculosis

Introduction: Reproducing Tuberculosis

The papers in this section address tuberculosis from a historical perspective. The power of historical contingency looms large at several levels of scale, showing how particular spaces of vulnerability are created. Beginning with the broad context of the tuberculosis epidemic wave that emerged in Europe in the 18th century the papers illustrate how the first worldwide epidemic of tuberculosis (Grigg 1958, Bates 1982, Stead 1997) reverberated through Indigenous communities in Canada and Aotearoa New Zealand in the 19th and 20th centuries. As the European tuberculosis epidemic subsided, its colonial extensions effloresced in response to the underlying fractures and inequalities that characterised each local encounter with the tubercle bacillus. Several papers locate tuberculosis within explicit state policies directed at the control and absorption of indigenous people, and within the paradigm of racial thought that prevailed in the early 20th century.

Padiak leads off this group of papers by addressing the circumstances that contributed to a precipitous decline in the burden of tuberculosis mortality in Britain in the 19th and early 20th centuries. She focuses on changes in the prevalence of TB morbidity, mortality, and case-fatality rates among British soldiers, for whom there was no measurable change in living conditions during her 80-year study period (1830-1913). Although it was a leading cause of death among soldiers, tuberculosis proved to be a relatively minor cause of illness. In fact, the drop in mortality is clearly linked to a substantial reduction in the tuberculosis case-fatality rate. Padiak suggests this enhanced survivorship among tubercular soldiers was either linked to improvements in their ability to resist infection, or to changes in the virulence of \textit{M. tuberculosis}, or both. Medical treatment may have played a role, insofar as the harm physicians did to their patients lessened. From a life cycle perspective, it is possible that successive cohorts of soldiers had more salubrious childhoods, which may have reduced the impact of adult tuberculosis (Noymer 2006, Noymer and Garenne 2000; 2003). A less virulent strain of the TB bacillus may have emerged (Brosch \textit{et al.} 2002) and there may also have been shifts in its interactions with other bacteria and viruses, such as influenza. Certainly, examining the conditions that contributed to the decline of the tuberculosis wave in Europe affords another view from which to assess the circumstances that permitted it to flourish there and elsewhere.

Hackett takes up the problem of the tuberculosis epidemic on a regional scale by examining how disparities in rates of tuberculosis emerged among Aboriginal groups in western Canada in the 19th and 20th centuries. He illustrates the fallacy of assuming that there was a single ‘tuberculosis problem’ among Aboriginal people in Canada, even though historically it was framed as a racial problem and came to be embedded in a discourse that represented Aboriginal bodies as fundamentally sick and degenerate (Kelm 1998, 2005, Waldram \textit{et al.} 2006, Herring and Sattenspiel 2007). Certainly the \textit{Mycobacterium tuberculosis} complex was present in the Americas prior to European contact (Salo \textit{et al.} 1994, Arriaz \textit{et al.} 1995, Braun \textit{et al.} 1998, Buikstra 1999, Konomi \textit{et al.} 2002, Roberts and Buikstra 2003). It may have given rise to epidemics in communities where conditions were conducive to outbreaks (Pfeiffer 1984, Saunders \textit{et al.} 1992). Did indigenous \textit{M. tuberculosis} play a role in the outbreaks in western Canada? (For opposing views on this question see Brosch \textit{et al.} 2002 and Stead 1997.) Hackett makes the case that disparities in tuberculosis rates within and between Aboriginal communities, and between Aboriginal and non-Aboriginal communities, were tied to differences in government policy, in the timing of the onset of the tuberculosis
epidemic, in the particularities of local geographies, and to varying degrees of economic and social marginalization.

Stephens provides a rare glimpse into the particular features of a single Anishnaabe community’s experience by unraveling the place of tuberculosis among the people of Walpole Island First Nation in the late 19th and early 20th centuries. Like Padiak, she assesses tuberculosis within the overall profile of mortality at Walpole Island, finding that it accounted for almost 70% of all deaths recorded in the parish register. Viewing tuberculosis as a single health problem masks the complexity of conditions that elevate, compound and sustain it in a community. At Walpole Island, multiple illness episodes converged and interacted with tuberculosis. These outbreaks were entwined with periods of deprivation stemming from the implementation of government assimilation policies that drastically changed local patterns of land use, access to resources, subsistence patterns and economic sustainability. In this way, syndemic conditions (Singer and Clair 2003) at Walpole Island triggered a health crisis that was the barometer and biological expression of inequality (Farmer 1999) produced through Canadian government policy.

The role of Canadian government policy in the spread of tuberculosis can be viewed at the finer level of particular institutions, as illustrated by Stoops’ detailed analysis of tuberculosis among pupils at Norway House Residential School in the first half of the 20th century. The residential school system was run as a joint venture between churches and the Department of Indian Affairs with the aim of undermining Aboriginal cultures by removing successive generations of children from their homes and instilling the values and practices of Canadian society away from the influence of their families (Miller 1996). Appalling conditions under which the children were housed in the school (overcrowding, poor nutrition and ventilation, heavy work loads, little access to medical facilities, fear and despair) promoted the spread of infection and the development of tuberculosis disease not only within the institution, but back into the students’ home communities. Cycles of decline and improvement at Norway House Residential School coincided with the actions of specific principals, Indian Agents, and medical officers in concert with the vagaries of government funding. Ultimately, tuberculosis at Norway House Residential School can be reduced to a matter of money, impelled by school officials’ attempts to perpetuate the institution itself. Here we see how the state policy of assimilation, facilitated by the churches’ chronically under-funded administration of residential schools, created key spaces of vulnerability for Aboriginal children in a broader circle of tubercular infection and disease in the Canadian north (Herring and Sattenspiel 2007).

Turning now to the ways in which state policies in Aotearoa New Zealand shaped diversity in the experience of Indigenous people, Finn analyses the context within which high rates of tuberculosis were sustained among Māori from 1918 to 1945. In seeking to understand why those rates were eight to ten times higher than rates recorded for Pakeha during the same period, she critiques and rejects race as an explanatory model. High rates of tuberculosis among Māori are, in fact, the complex product of interacting social pathways in the first half of the 20th century that served to focalise infection, and ultimately TB disease, among them. The excessive burden of TB among Māori is more properly understood as interacting elements in the colonial process: the product of class and marginalisation, expressed through social structural inequities in economic opportunity that lead to hardship, inequality in access to housing and land, and reduced access to health care for Māori. Finn’s case study of tuberculosis in the Rotorua region points to microsocial factors that may explain suggestive though inconclusive evidence that tuberculosis rates may have been higher among the more disadvantaged, rural-living Māori compared to their more urban counterparts. With a
particular focus on the quality of housing, she shows how state policies explicitly designed to address inequalities further perpetuated those differences. State priorities, such as the tourist industry, served to promote TB transmission among rural Māori by creating differential access to housing and labour opportunities. Her work adds to the growing literature on the direct and indirect ways in which colonial processes, nation building agendas, and racism contributed to the poor health of Indigenous people.

References


Chapter 9
The Contribution of Tuberculosis to the Mortality of British Soldiers
1830-1913
Janet Padiak

There is no doubt that tuberculosis was a major cause of mortality in the centuries up until the middle of the 19th century. Known under guises such as consumption and phthisis, terms that described the wasting of its victims, the disease was indiscriminate about who was infected. It was a disease of young adults in the prime of their lives, of infants, of children, of older adults; it decimated those that crowded into the dirty, pestilent cities as well as those inhabiting isolated rural areas. Tuberculosis killed off rich men and kings and was also a disease of the destitute huddled into makeshift shelters. From peak levels in the middle of the 19th century the disease began to wane. No one knows why although there have been many hypotheses put forward (Murray 2004). Many have cited the improvements in sanitation and public health (e.g., Szreter 1988), others have supported improvements in socio-economic conditions and nutrition (McKeown 1976), some have suggested climate (Curtin 1989) and yet others have suggested evolution of the virulence of the bacillus that causes the disease (Davies et al. 1999). Few argue for a role for medicine in the reduction of tuberculosis, as improvement in mortality occurred before understanding of the etiology of the disease and the discovery of \textit{Mycobacterium tuberculosis} by Koch in 1882, and well before any effective medical intervention, pharmaceutical or therapeutic (Fairchild and Oppenheimer 1998). Part of the reason for an absence of consensus on the causes is the erratic nature of the decline of the disease. In some areas, female mortality declined before male yet in other areas male mortality declined first (Smith 1988). Some studies show declines in rural areas predating those of cities, yet others show the opposite (Long 1948). Despite the range of arguments for the reduction in tuberculosis, most agree that reductions in deaths from tuberculosis were a major force in the decline of population mortality that began in late 19th century European and North American populations (McKeown 1976, Smith 1988, Mercer 1986). By the eve of WWI, the national statistics of many European and American countries were showing a decline in tubercular deaths.

This paper investigates the levels of the disease during this period among the troops of the British army, based on archival records of surgeons assigned to its regiments and annual reports published as part of the British Parliamentary Papers. Tuberculosis was one of many killer diseases affecting soldiers, many of which were infectious in etiology and, because all illnesses and deaths were recorded by the army, it is possible to consider tuberculosis relative to all other causes of sickness and death. When considered as a proportion of all deaths, tuberculosis can be seen as a component of the total burden of disease, the amount of disease that the army had to contend with on an annual basis. Among soldiers, tuberculosis did not decline in concert with other causes of death but went from being a truly onerous disease burden in the 1830s and 1840s, causing 40 to 50 percent of soldiers’ mortality, to a moderate burden after the turn of the 20th century, accounting for 13 percent of the soldiers’ deaths.

The British army provides a particularly interesting case study of tuberculosis for a number of reasons. First, in the early portion of the 19th century, the soldiers’ tubercular mortality was much higher than that of their civilian peers of the same age and sex; five decades later, it was much lower. Over time, both civilians and the military men were dying less from this disease; however, the forces driving tubercular mortality downwards seem to be especially effective in the army. A second reason that the army provides an interesting study is because the
regimental surgeons recorded morbidity as well as mortality and this allows a rare glimpse of the levels of sickness from the disease. In addition, the restrictions, conventions and consistencies of army life permit elimination of some factors that might affect mortality change. For example, because soldiers’ duty, activity levels and diet changed minimally during these decades, analysis of health improvements can eliminate improvements in socio-economic status as a factor. Another reason that the army offers excellent insight into 19th century health is because military mortality recording predates that of the general population. Although civilian death registration began in England and Wales in 1838, causes of death by age and sex were not available until 1851 (Dudfield 1907), but the army had begun recording sickness and mortality in colonial stations as early as 1818.

For this study, only ordinary soldiers (no officers) stationed in England, Scotland and Ireland were included. From 1830 to 1847 the study includes data from 5,000 to 6,500 soldiers per year and from 1859 to 1913, the data are for 60,000 to 120,000 soldiers per year; there are no data available for the period from 1848 to 1858. Altogether over 600 causes of illness and over 150 causes of death are recorded. There may be some attributions of death that could be challenged by medical knowledge today, but overall causes of death are reliable for that time as most soldiers’ deaths were followed by autopsies. Less than one percent of the deaths were recorded as due to unspecified cause.

In the 1830s and 1840s, tuberculosis was believed to be a hereditary disease, perhaps activated by some sort of ‘excitement’ such as immoral living, heavy alcohol consumption or the breathing of putrid air (Smith 1988). The concept of tuberculosis as an infectious disease began to gain some popularity in the 1860s, following Villemin’s work in 1868 and confirmation that it is caused by a specific micro-organism by Koch in 1882. Much of the confusion over the infectious nature of tuberculosis was because the tubercular bacillus could become active in any number of organs or locales in the body. For those working with death records in the past, this means that knowledge of the terminology that was applied to these different manifestations is essential (Dudfield 1907). For this study on tuberculosis, several conditions were included as tubercular manifestations: scrofula, phthisis, tabes mesenterica, tubercular meningitis, abscessus psoas, morbus coxarius, apostema lumbare, tubercle and tuberculosis. The term consumption was not used in military medical terminology. Tuberculosis, tubercle, phthisis and scrofula caused the vast majority, accounting for 97 percent of the 9937 tubercular deaths in this study.

Soldiers’ tubercular mortality

Once there was sufficient cause of death data to allow comparison of civilian and military levels, it was quite clear that in the late 1830s and 1840s, soldiers stationed within the UK had a higher mortality rate than civilian males of the same age group (Lever 1839, Balfour 1845). Troop death rates hovered around 15 per 1000 men per year and tuberculosis was the dominant cause of death (Figure 1). At the beginning of the 1830s, five to seven soldiers per 1000 men per year died of some form of tuberculosis. There were great swings from year to year in the number of tubercular deaths but overall the levels were increasing. By the middle of the 1840s, between seven and ten soldiers per 1000 men died of tuberculosis each year. Morbidity records show that many other respiratory infections and diseases also rose at this time; there were also several epidemics of influenza during this period that caused a large amount of morbidity (Padiak and Herring in review). The rate for civilian males between the ages of 15 and 35 was only five per 1000 men per year, much lower than that for the army (Figure 2). Although it is possible that there are methodological problems in cause-of-death attribution in these early
years of civilian mortality registration, it does appear that the spike in the late 1830s and early 1840s was restricted to the military. A similar spike appears in tuberculosis levels for soldiers stationed at the Gibraltar station in the Mediterranean (Padiak 2004), and there is a swell in tuberculosis deaths in the 1830s for New York City (Long 1848).

**Figure 1** British soldiers’ mortality rates per 1000 men per year, from 1830 to 1913, for all causes and from tubercular diseases only.

**Figure 2** Tubercular mortality, rate per 1000 men per year, British soldiers and civilians, 1830 to 1913. Data for civilians from Lawson 1887 and from Annual Report of the Registrar-General 1913, p 7, table LXV; quinquennial except for 1911 and 1912. Dashed line indicates averaged data.
It was expected that, as a group, soldiers would have lower levels of ill health than their civilian peers. Because a physical examination was required for enlistment, any men with visible signs of disease, poor development or disabilities would be prevented from entering the army. This selection process eliminated about 25 to 35 percent of men who desired to become soldiers (Report on Recruits 1835, Skelley 1977). Once in the army, soldiers were under the care of regimental surgeons who were responsible for maintaining the troops in good health. The ready presence of a doctor, free of charge, was a benefit that was unequalled in civilian life at that time, although the aggressive therapies of the 1830s and 1840s made this a dubious advantage (Padiak and Herring in review). Nonetheless, the troops were inspected on a weekly basis and the sick were segregated from the healthy in the regimental hospital. Soldiers also had the advantage of a better diet than that of the average Briton. Their daily rations included almost a pound of meat in addition to bread, vegetables, coffee and ale; most labourers were lucky to get meat once a week (Lever 1839, Skelley 1977). So there was some consternation when the early reports showed the high mortality of the troops (Lever 1839, Tulloch 1841, Balfour 1845).

There were several suggestions for the reasons for the high rates of tuberculosis and other fatal diseases in the army. Guard duty on damp nights was considered but comparisons to death rates of the London police force, subject to more severe night duty but with lower rates of death, demonstrated that this was not the factor (Lever 1839). The clothing of the soldiers was also hypothesised as a possible reason for high tuberculosis rates (Lawson 1887). Civilian labourers, when becoming overheated, could remove layers of clothing to permit the evaporation of perspiration. Soldiers, however, were required to retain their full uniform, including belts, knapsacks and white trousers, at all times. It was noted that the linen shirts beneath the heavy jackets quickly became soaked and, when parade or labour was finished, the soldier quickly removed the sodden articles, exposing his damp body to the weather. The white trousers, requiring frequent laundering, were often damp because of incomplete drying and this could contribute to fevers and respiratory diseases (Lawson 1887). Changes in clothing in the 1850s could have alleviated these problems and reduced the rate of disease. Others considered the frequent daily periods of inactivity inherent in military life to be a contributor. Idleness led to unhealthy activities in taverns, such as drinking, gambling and consorting with prostitutes, which could reduce the resistance of a young man to disease (Rawson 1887). Crowding and poor ventilation, which together created foetid atmospheres in many urban barrack rooms, were generally agreed to contribute to the ill-health of the soldiers stationed in towns but did not explain the high rates for those barracked in rural areas.

Not much is known about the health of the military from 1848 to 1858. Without funding, army medicine had declined, becoming leaderless and disorganised (Lankford 1980); statistics were only intermittently collected and no reports were made. After the public response to the large number of unnecessary deaths due to disease during the Crimean War, parliament created and empowered the Army Medical Department (Cantlie 1974). In 1859, troops’ health began being recorded again, this time subject to greater intensity, and submitted to London weekly rather than quarterly. With the first release of statistics, it was clear that there had been a decline in soldiers’ mortality. Rates had fallen about a third from those of the 1840s and were below the more favourable levels of the early 1830s, even before the new Army Medical Department had a chance to implement any changes to the soldiers’ conditions of enlistment. This decline in mortality is largely attributable to decline in deaths from tuberculosis. However, although absolute numbers had declined, the disease was still responsible for over 30 percent of the soldiers’ overall mortality. At the same time, civilian mortality from tuberculosis had changed very little and, as a result, the two rates were quite close.
Soldiers’ mortality rates from all diseases and from tuberculosis were relatively static for the next two decades; so was tubercular mortality for their civilian peers. In the 1880s, around the time that Koch was isolating the micro-organism responsible for the disease, a steady decrease in tubercular deaths and in overall mortality began. By the first decade of the 20th century, the soldiers’ mortality rate had dropped to around 3.4 per 1000 men per annum and tuberculosis was responsible for less than 0.4 deaths per 1000, or one death per 2400 soldiers per year. Rates for civilian males from the age of 15 to 35 also declined, but at a much slower rate, so by 1911 and 1912, the rates for civilians were four-fold that of the troops, at 1.77 death per 1000 men per year.

The burden of tuberculosis can be assessed as a contributor to overall mortality by considering the percent of soldiers’ tubercular deaths as a proportion of deaths from all causes (Figure 3). After rising in importance as a cause of death in the 1830s, tuberculosis declined by the 1860s and then again in the three decades before WWI. In the 1830s, the measure of tuberculosis on the total disease burden was over 50 percent (Table 1), certainly constituting the major contributor to annual mortality. Each succeeding decade, into the new century, shows a reduction, after which tuberculosis accounted for only 13 percent of all deaths. This reduction in importance of tuberculosis as a component of all deaths was occurring as deaths from all causes of mortality were declining. The result is that in six decades since the 1830s, the tubercular death rate of the soldiers had decreased to one twentieth of its previous lethal level. Not only was tubercular mortality declining in absolute levels, it was also declining in importance relative to all other causes of death.

![Figure 3](image-url) Percent contribution of tuberculosis to total mortality of soldiers, 1830 to 1913. Data from 1848 to 1858 are not available and are shown as averaged values.
Table 1  Tuberculosis as a percentage of causes of deaths and illnesses by decade, for the soldiers of the British army 1830 to 1913.

<table>
<thead>
<tr>
<th>Decade</th>
<th>Total Mortality Rate per 1000</th>
<th>Tubercular Mortality Rate per 1000</th>
<th>Percent Tubercular Deaths to All Deaths</th>
<th>Total Morbidity Rate per 1000</th>
<th>Tubercular Morbidity Rate per 1000</th>
<th>Percent Tubercular Illnesses to All Illnesses</th>
<th>Total Number of Soldier Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>1830-9</td>
<td>14.7</td>
<td>6.1</td>
<td>41.7</td>
<td>847.9</td>
<td>7.4</td>
<td>0.9</td>
<td>115928</td>
</tr>
<tr>
<td>1840-7</td>
<td>15.4</td>
<td>7.8</td>
<td>50.5</td>
<td>813.3</td>
<td>10.7</td>
<td>1.3</td>
<td>198447</td>
</tr>
<tr>
<td>1850s</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1860-9</td>
<td>8.7</td>
<td>2.9</td>
<td>33.0</td>
<td>617.8</td>
<td>9.9</td>
<td>1.6</td>
<td>694805</td>
</tr>
<tr>
<td>1870-9</td>
<td>8.3</td>
<td>2.5</td>
<td>29.9</td>
<td>654.4</td>
<td>11.2</td>
<td>1.7</td>
<td>850718</td>
</tr>
<tr>
<td>1880-9</td>
<td>6.2</td>
<td>1.7</td>
<td>27.3</td>
<td>571.2</td>
<td>6.6</td>
<td>1.2</td>
<td>928071</td>
</tr>
<tr>
<td>1890-9</td>
<td>4.3</td>
<td>0.8</td>
<td>19.1</td>
<td>526.7</td>
<td>3.0</td>
<td>0.6</td>
<td>1015547</td>
</tr>
<tr>
<td>1900-13</td>
<td>3.4</td>
<td>0.4</td>
<td>13.1</td>
<td>362.3</td>
<td>2.6</td>
<td>0.7</td>
<td>1717662</td>
</tr>
</tbody>
</table>

Tuberculosis as a cause of morbidity

Tuberculosis as a morbidity burden can be considered in the same way as mortality. In the regiment, morbidity was any condition, sickness or injury that required special treatment or observation and caused the soldier to be away from duty; morbidity could include such diverse causes as rashes, sprains, fevers, hernias, epilepsies and psychological problems, as well as tuberculosis. Sexually-transmitted diseases were also causes for admissions to the hospital but because they caused large amounts of morbidity and almost no mortality among soldiers, they are removed for this analysis. Sick soldiers were admitted to the regimental or station hospital and segregated from the healthy members of the regiment until well; those deemed incurable were sent to an invalid hospital.

In the 1830s, the average morbidity rate was 847 admissions per year per 1000 troops, a rate that translates to an illness for every soldier every 14 or so months (Table 1). The morbidity rate declined steadily throughout the century and by the 19th century it had reduced by more than half to 362 per 1000 soldiers per year. Morbidity due to tubercular diseases was 7.4 and 10.7 admissions per 1000 in the 1830s and 1840s respectively, accounting for only a very small amount of sickness. This level changed very little until after 1880 when it declined rapidly. In the new century, less than three soldiers per 1000 per year were diagnosed with a tubercular disease.

Tuberculosis was only ever a minor morbidity burden, never causing more than two percent of total sickness. There were several cause of illness categories that caused great numbers of hospital admissions, such as fevers, injuries, eye infections, respiratory illnesses, rheumatisms; most were non-fatal conditions. Even in crowded and ill-ventilated barracks, it appears that the tubercle bacillus did not transfer as readily as infectious organisms that cause bronchitis, continued fevers, influenza or other droplet borne infections. Fortunately for the healthy members of the regiment, it was army policy to separate sick soldiers from the well wherever possible, preventing unnecessary transmission. The other potential pathway of transmission of the tubercle bacillus, through contaminated milk or meat, was unlikely in the military. Milk was not a part of the soldiers’ daily ration and was rarely consumed. Meat was purchased on the regimental scale under the auspices of the officers (who consumed the same beasts) and quarterly reports were made on the quality of the diet. The large amount of mortality from this disease, therefore, lay not in the number of men who acquired the disease but in the potential of the disease to kill those who became infected.
While fluctuations in mortality can be artifactual, general decline in mortality from a disease can arise from two directions. First, there can be a reduction in mortality because fewer people acquire the disease. The second possibility is that the same proportion of the population acquires the disease but something alters such that there is an improved survival outcome. These shifts may be the result of greater host resistance, a less virulent form of the pathogen, a change in the conditions that favour infection or the availability of an environment that favours a full recovery (Reeves 1985). As shown in Table 1, from the 1830s to the 1840s, soldiers were acquiring tuberculosis at greater rates and in greater numbers, and this contributed to a higher overall death rate, but when the case fatality rate is considered, an improvement in mortality outcome is seen (Table 2). For each 100 cases of tuberculosis identified by the regimental surgeons in the 1830s, there were 82 deaths. This can be compared with 72 deaths per 100 cases the following decade, a minor reduction. In the 1860s, the levels of morbidity actually increased and so did the proportion of tuberculosis relative to all other causes of morbidity, but case fatality dropped to 28 deaths per 100 cases. The level of case fatality remained fairly constant in the next four decades as morbidity and mortality remained steady then declined in concert. After the turn of the century, the improvement in mortality outcomes outpaced reductions in levels of the disease and again the case fatality rate declined to 17 deaths per 100 cases.

Table 2. Case fatality rate (deaths per 100 cases of illness) for tuberculosis among British soldiers from 1830 to 1913.

<table>
<thead>
<tr>
<th>Year</th>
<th>Case Fatality Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1830-9</td>
<td>82</td>
</tr>
<tr>
<td>1840-7</td>
<td>72</td>
</tr>
<tr>
<td>1850s</td>
<td>n/a</td>
</tr>
<tr>
<td>1860-9</td>
<td>28</td>
</tr>
<tr>
<td>1870-9</td>
<td>21</td>
</tr>
<tr>
<td>1880-9</td>
<td>24</td>
</tr>
<tr>
<td>1890-9</td>
<td>27</td>
</tr>
<tr>
<td>1900-13</td>
<td>17</td>
</tr>
</tbody>
</table>

The decline of tubercular mortality

Many suggestions have been made by investigators to explain the decline in tuberculosis deaths in the 19th century. Some, including McKeown (1976), support the hypothesis that improvements in the food supply and its sequela, improved nutrition, were important in allowing individual members of the population to become more resistant to infection by the disease. Others (Szreter 1988, Cronjé 1984) have argued that improvements in water supply, waste removal, food regulation and quality, and domestic cleanliness were crucially important in creating environments that discouraged transmission of infectious diseases. Improvements in the soldiers’ barracks environment, which occurred after the creation of the medical department in 1858, likely contributed to the improvement in mortality that occurred after the 1880s. However, the decline in tuberculosis mortality that occurred before the 1860s cannot readily be attributed to these improvements. Some argue that social capital, including education and welfare programs, were an important component for mortality decline, particularly when it prevented infections in children that might affect their future robustness as adults (Smith and Lynch 2004, Taylor et al. 1998). It is possible that as earlier cohorts of
soldiers had experienced illness events in childhood, especially primary infection with the
tubercular bacillus, that predisposed them towards full expression of the disease as adults.
Another argument rests on the suggestion that the understanding of the aetiology of the
disease, even in the absence of antibiotics and other effective chemical therapies, permitted
basic precautions to be taken to hinder the spread of the disease (Murray 2004). In the
1860s, Villemin’s work demonstrating that tuberculosis is an infectious disease rather than a
hereditary or constitutional disease and, later, Koch’s work identifying the actual organism,
would allow medical men to implement precautionary measures (Villemin 1868, Koch 1882).
Although it is likely that this new knowledge was crucial to a reduction of the disease towards
the end of the century, it does not explain some of the early changes in tuberculosis mortality.

These suggestions for the decline of tuberculosis mortality are not exclusive and several may
be operating at the same time. However, many hypotheses depend on the decline of tubercular
mortality as a result of a decline in tubercular morbidity. For the soldiers, mortality declined
before morbidity declined, suggesting that it was the outcome of a morbidity event that
altered first; tubercular morbidity only declined later in the century. Of the suggested
mechanisms, only those that explain changes in mortality as a result of greater individual
resistance are applicable to the decline of soldiers’ tubercular mortality in the 1840s and
1850s. Improved nutrition for soldiers or the improvement of social capital investments such
as education and welfare support would develop healthier constitutions better able to rebuff
disease. Because of the quality and regimentation of the soldiers’ daily diet, and their
unchanged socio-economic status, improved nutrition is not a possible agent for change.
Differential health experiences of successive cohorts of soldiers is a persuasive argument,
however.

There are two other possible scenarios that would explain the decline of mortality before a
decline in morbidity. First, it is possible that there was greater virulence to the infectious
organism during the late 1830s, a virulence that could cause higher fatality rates. This greater
virulence might have been the result of shift in the bacterium itself or it might be the result of
interactions with other micro-organisms such as the influenza viruses that were causing
epidemic waves during this decade. The other possibility is that medical care contributed in
some way to the higher mortality of the decade. Investigation into regimental medical care
during the 1830s and 1840s has shown that even minor ailments such as influenza elicited
aggressive therapies such as bloodletting and purging (Padiak and Herring in review). In the
era before the understanding of asepsis and professional nursing, it is possible that hospital
conditions could aggravate serious illnesses, especially when the patient was subjected to
blood loss and severe intestinal depletion. Changes in hospital practices that alter outcomes of
morbidity events could explain the patterns seen in these data.

Whatever the causal mechanism that governed the decline in soldiers’ tubercular mortality, it
was an astounding success. If the rates had remained the same from the 1860s until the eve of
WWI, an army of 100,000 would have had an additional 7,000 deaths from tuberculosis
alone. Even with the improvement, there were still 30 to 50 deaths per year in the army in the
first decade of the 20th century. However, by WWI, tuberculosis was no longer the leading
cause of death; it had fallen to third. Injuries and accidents became the number one cause of
death for soldiers, followed closely by respiratory infections.

The onerous burden of tuberculosis borne by the soldiers in the 1830s and 1840s, where
sometimes half of the deaths were a result of the same infectious organism, declined
drastically by the turn of the century. By the onset of WWI, tuberculosis was responsible for a
manageable 13 percent of deaths. Morbidity also was declining, to one quarter of the levels of
only four decades earlier. There was no reason to expect that this improvement would not
continue, perhaps to a very small percentage of deaths. With the medical department first focusing on reducing deaths among soldiers who had an active case of the disease, and then subsequently focusing on reducing the conditions that seem to favour initial infection, tubercular mortality declined among the soldiers.

Acknowledgements

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References

Note: NAUK refers to files in the National Archives of the UK in Kew, Richmond, Surrey.


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Chapter 10

Tuberculosis Mortality among the Students of St Joseph’s Residential School in 1942-43: Historical and Geographical Context

Paul Hackett

Between May of 1942 and June of 1943 seven young Indian children died at the St Joseph’s Roman Catholic residential school at Cross Lake, in the Norway House District of Manitoba (Figure 1). Multiple deaths of students at the school were by no means unprecedented; as recently as February of 1930 twelve students and one employee had perished in a fire at the school. In the deaths of the early 1940s no single incident triggered this mortality, however more than half were linked to a common cause. Four of these deaths were attributed to some form of tuberculosis (TB) by school or medical officials. In the span of just over a year, out of an average enrolment of ninety-nine, four students, all between the ages of seven and twelve, had died of this disease.

Figure 1 Cross Lake Hinterland

There can be no doubt that the loss of these children was tragic for their families and for their communities. However, TB-related deaths such as these were by no means exceptional, as children enrolled at residential schools in western Canada had been dying of the disease since the schools first appeared in the late nineteenth century (Miller 2000, Milloy 1999). The relationship between the church-run schools and the disease had long been common knowledge among parents, and Indian Commissioner W. M. Graham summed up this
understanding in a letter to Duncan Campbell Scott, the Deputy Superintendent General of Indian Affairs, dated February 10, 1925. Graham observed, “I quite often hear from the Indians that they do not want to send their children to school as it is a place where they are sent to die.” The parents of the children at St Joseph’s may have entertained similar feelings about that school two decades later.

On another level, however, the circumstances surrounding these four deaths are illustrative of important trends in Indian health in western Canada’s residential schools. First, these deaths demonstrate the inability of the federal government and the churches to protect the children who attended residential schools from tuberculosis, even after acknowledging the problem for at least half a century. Secondly, they highlight the broader conflict between the medical personnel who were tasked with fighting the disease, and the agents of the church who sought to run the schools as economically as possible. Finally, they exemplify the differences in health services provided by the federal government to different parts of western Canada, based on relative location, and access to limited resources.

**Government Policy and Tuberculosis**

Beginning in the 1880s a network of residential schools emerged across western Canada, the product of a partnership between various religious orders and the Canadian government (Milloy 1999). Typically, the government provided the land and building for the school, teaching materials and travel expenses for the students, as well as a per capita grant. In turn, the church was responsible for covering all operating costs for the facility out of those grants (Kelm 1998:60). Nominally, their goal was to educate the Indian children of the region, but in reality they were designed as much or more to inculcate Western culture in the children, including Western religion, customs and language, as a means of transitioning the Indian people into a new way of life.

Almost from the start, the residential schools of western Canada were breeding grounds for TB. Overcrowding, deteriorating infrastructure, inadequate ventilation, and poor food all contributed to extremely high rates of TB-related mortality (Milloy 1999:51-3). By the 1890s field medical officers were alerting the Department of Indian Affairs to the extent of the problem and the likely causes of TB in the schools. Most focussed on the harmful effects of civilisation, conditions in the schools, and the general tendency of the Indians to contract the disease. They also suggested ways in which conditions could be improved, particularly with respect to the lack of adequate ventilation in the schools (Orton 1893). By the mid-point of the decade, the Department of Indian Affairs in Ottawa was well aware of the situation, though it seems not to have made much of an effort to solve the problem.

Things did not improve with the new century. In 1907 the Chief Medical Officer of the Department of the Interior, Dr Peter Bryce, found TB mortality rates between 24 and 75 per cent among former students of residential schools in the west (1907). Two years later Bryce worked with Dr J. D. Lafferty to inspect children in eight Alberta schools, and discovered that TB was extremely common among children in those schools (Bryce 1922). Bryce placed much of the blame at the feet of the schools and the administrators, focussing on poor ventilation, overcrowding, and a lack of exercise afforded the students (1907:19). However, historian John Milloy has noted that the federal government was complicit in that it failed to exercise proper oversight of the churches (1999:55-6). Moreover, he argued that the order in council of 1892, which established a rigid funding scheme that paid a set amount per pupil, set in place the conditions that led to the disaster observed by Bryce by underfunding the
schools. This forced school officials to cut corners in order to save costs, placing the health of the children in jeopardy.

Bryce’s alarm did press the government to make some administrative changes to the Indian school system, which lessened TB mortality in the schools (Sproule-Jones 1996:201,217). In particular, strict admission policies (not always observed, however), minimal standards for school conditions and new funding regulations ensured that the disease would never again have the same terrible impact on the students as it had in the first decade of the twentieth century. The Department also took over full responsibility for maintaining the health of the Indians on the reserves and the schools (Sproule-Jones 1996:218). However, the per capita grant system, and the constraints on the churches to pay for all operating expenses out of this grant, remained. Without additional funds for operating the schools (or, alternatively, without reducing the costs) the incentive remained for school officials to circumvent the regulations, either by taking on more students than was considered healthy, by overworking them or by providing sub-standard living conditions.

Despite the changes to the system, there would be no drive to eliminate TB from the residential schools for several decades. Strapped for funds, Ottawa rationed treatment and focussed on prevention, an imperfect policy that proved inadequate to the task of keeping the disease out of the schools. Rather than establish its own dedicated TB treatment facilities, the Department of Indian Affairs paid to send a very few TB cases to municipally or provincially-run facilities for treatment, and reserved an even smaller number of beds for TB-treatment in departmental hospitals. As Deputy Superintendent Duncan Campbell Scott stated bluntly in 1926:

> The cost of adopting an extensive system for the suppression of tuberculosis amongst the Indians would undoubtedly be very great, but until it becomes possible to remove the existing financial handicap, we cannot hope to take the radical steps necessary toward the elimination of tuberculosis.  

As a result, the number of Indians in treatment, children or otherwise, never approached what was necessary until the 1940s.

The inability of Indian Affairs to address the issue of TB in the residential schools was made clear in the Department’s annual report for 1934-35. TB surveys were being carried out in southern schools, but little could be done with the results. The report outlined the progress that had been made:

> A large number of residential schools have been surveyed and resurveyed. The pupils are all examined, and most of them, at any rate all who are suspected of being tuberculous, are subjected to X-ray examination. They are divided finally into several grades, ranging from the definitely tuberculous, who are quite unfit for school life, to definitely clear of active tuberculosis.

Despite these efforts, the report also noted that there were no federal funds available for the sanatorium treatment of those who were found to have active disease.

**Provincial Patterns of TB**

The failure of the Canadian government to adequately address TB in the residential schools and on the reserves left the matter mainly in the hands of the provinces. The Manitoba government could hardly ignore the issue, as, in their estimation, the presence of the infection within the provincial boundaries constituted a potential public health menace. As Dr David A.
Stewart of the Manitoba Sanatorium Board observed, increased expansion of white interests into the north carried the risk of transferring TB from the Indian reserves to the non-Native population, an observation he made on multiple occasions. Writing in the Canadian Medical Association Journal, Stewart noted:

These Indian reservations and settlements never were water-tight or disease-tight compartments, and in a new day of easier travel are becoming less and less so. And it is true that any disease in any remote corner of a province is disease of the province; that the province will not be clear of any disease nor safe from its menace until every group is clear and safe; and that in health matters no man liveth unto himself and no man dieth unto himself (Stewart, 1936).

Although the doctor noted that there was a moral responsibility on the part of non-Native people to address the situation, the potential public health menace was sufficient grounds for action in its own right.

If the Manitoba government had a strong motivation to address Indian TB, it lacked authority to use provincial resources to assist people who were not provincial citizens. Instead, it relied primarily on two sources of funds to identify and treat those Manitoban Indians with TB. Charitable donations from organisations such as the Christmas Seal foundation enabled the province to fund limited TB surveys and treatment among the Indians of the province as early as 1930 (Stewart 1999:166). As well, the Canadian government reimbursed the province for a few Indian people who were admitted to provincial sanatoria, at least as early as 1915, and contributed limited funds for x-ray surveys of some reserves and schools.

Since these private and federal funds were always in short supply, such programs were directed at those who posed the greatest threat to the broader society, creating a pronounced geographic pattern in Indian treatment within the province of Manitoba. Essentially, case-finding surveys and treatment were carried out only on those reserves and schools in the south, or at least along the settlement frontier. The other condition for selection of the communities to participate in these surveys was access, and TB clinics were only conducted in residential schools and on reserves that lay along the existing provincial road and rail transport systems. As a result, the bulk of the children being removed and treated were from the south until the latter part of the 1940s (Ross and Paine 1939:181). This incomplete spatial distribution of treatment can be seen in the communities and schools selected for the 1937 survey carried out by the provincial government, which were predominantly limited to the southern part of the province (Figure 2).

This spatial differential would have had real consequences for the distribution of TB in the province, favouring those in close proximity to non-Native settlements, and working against those who were more isolated by the definition of the government. For instance, the first survey conducted at the Fort Alexander Residential School and reserve in southeastern Manitoba in June of 1930, found conditions that were “medieval,” and child mortality that was appalling (Stewart 1999:94). In 1935 Ross and Paine (Ross 1967:2) found that three percent on the reserve had active and infective tuberculosis, and believed that the majority of those would die of the disease, as there would be no treatment. By 1937, however, all of the suspected cases of latent TB in the Fort Alexander Residential School had been removed to a local preventorium for treatment, and by 1939 those from the reserve with active disease were being sent to a nearby sanatorium.
In contrast, the high rates of TB in the northern part of the province were well known and accepted in lieu of providing treatment. In a report to Ottawa written in 1925, Dr E. L. Stone observed that the Indians of the Norway House Agency were “heavily affected with tuberculosis” and were “a consumptive people,” with Cross Lake being in the worst circumstances (1989:241). Equally telling, in performing the TB examinations for the residential school children, Stone could not recall a single child from any reserve in the district, save Island Lake, who would have been admitted had the doctor complied with the regulations dictating he deny entry to those infected with TB (pp.247-8). Thus, he rejected only those with apparent active disease, while those whose TB was dormant were allowed to enter. The potential for reactivation of the disease in an overcrowded environment with high stress levels was very high. Putting a rosy picture on an otherwise bleak situation, Stone noted of the students “They do quite as well in the schools as they would do outside, but, at that, there are too many deaths of pupils during their education” (p.248). Incredibly, instead of acknowledging its own failures, Ottawa chose to place the blame on the Indians themselves. In 1928 the Department of Indian Affairs annual report observed that “There are certain
districts, where the Indians are of such primitive and nomadic habits and live over such an extended area that it is impossible to do more than send a doctor once a year to visit them when they are collected to meet the department official who pays the annuity money.”

Under these circumstances, the doctor did nothing more than treat emergent cases of disease in situ, and vaccinate and lecture the Indians on health and sanitation. Long-term treatment of TB was out of the question.

Additional funds to combat TB among the Indians in southern Manitoba (and across Canada) were made available by the federal government in 1937. Following a joint federal and provincial TB conference held in Ottawa in June, $50,000 was immediately added to the departmental appropriation, and the departmental budget was thereafter increased annually to provide added funding for case-finding and treatment (Wherrett 1977:114). The following year Ottawa finally began to authorize sanatorium treatment for “Manitoba Indians” in substantial numbers at the rate $2.50 per day for each Indian person treated in a provincial facility. In 1939, in response to the need for more beds, Indian Affairs purchased the Anglican Church’s Dynevor Indian hospital at St Peter’s, just to the north of Winnipeg (Stewart 1999). In December of 1939 the newly converted 50-bed TB hospital reopened under the administration of the Sanatorium Board of Manitoba, becoming the first of several tuberculosis hospitals reserved for Aboriginal people that were opened by the federal government through the 1940s. The Department also built a 20-bed hospital and sanatorium at the Fisher River Agency (Figure 3). Though desperately needed, both of these new facilities reinforced the existing geographic concentration of TB services for Manitoba’s Indians, favouring those whose disease posed an immediate threat to the non-Native population.

In The Miracle of the Empty Beds, George Wherrett (1977:114) characterized the Ottawa conference as a turning point in the fight against Indian TB. Wherrett had been the Executive Secretary of the Canadian Tuberculosis Association at the time, and so compared to the earlier era the next decade would have seemed like one of continuous progress from an overall public health standpoint, if not in terms of the health of the Indian people themselves. In fact, the public health benefits for those of the north were a long time coming. The recommendations emerging out of the Ottawa TB conference of 1937 called for “the clearing of residential schools of active tuberculosis cases, the examination and survey of the more accessible reserves, and the isolation and treatment of the Indians found to have active tuberculosis.”

The program set out two specific goals, neither of which applied to the people of the Norway House Agency. First, they were “to control, if not eradicate, tuberculosis in accessible residential schools.” Secondly, any remaining money would be used “to attack those reserves in most intimate contact with the general population, and those where a small expenditure would serve to control the disease effectively and completely” (Stone 1943). The spaces in the Dynevor hospital would be taken up by people from the south. Those in more isolated communities would continue to have to fend for themselves for another decade.

Death at Cross Lake

It was in this context of unequal access to TB treatment that events unfolded at St Joseph’s between the spring of 1942 and the following summer. It began in May of 1942 with the death of a young girl, Margaret B., the first of four children from St Joseph’s Residential School (Figure 4) to die of TB over a thirteen-month period. She was six years old in December of 1940 when she was admitted to St Joseph’s from God’s Lake, a small, isolated, community to the east of Cross Lake. There is no evidence of earlier illness, but on March 17th she complained of feeling ill. Margaret B. looked sufficiently so to the school’s nurse, Sister
Francoise Therese, that the girl was placed on bed rest in a private ward, and given abundant food and cod liver oil. At that time St Joseph’s Principal, Father G. E. Trudeau, did not deem that she appeared ill enough to call the doctor, who in any event, it was argued, would not have been able to come to the school at that time of year due to poor travelling conditions. The Principal’s evaluation notwithstanding, when Dr Cameron Corrigan finally arrived from Norway House on the 24th May, her condition was considered too far advanced for treatment at the closest hospital at Norway House, and so Margaret B. was left to recover or die in the school. She died of an undifferentiated form of TB on May 29th at the age of nine.

The second to die of TB was an eight-year-old girl, Lilly R., who was a member of the local Cross Lake band. She had entered the school in April of 1940, at the age of five or six. In her case the quarterly returns indicate that she missed no school prior to her death on February 25, 1943, however the inquest that followed her passing revealed that she first fell ill at 4pm on the 8th of that month. As with Margaret B., Lilly R. was seen by the nurse, Sister Therese, and was immediately placed in the infirmary. She was given one half tablet of aspirin every four hours, and an ice bag for her head. Once again, Corrigan was not called, this time because the Principal believed that the doctor would arrive “any day.” Corrigan never saw her before her death.
Unlike the earlier case, neither the quarterly returns nor the memorandum of inquiry mention the cause of death of Lilly R. Instead, they simply state that she died on February 25th. Even so, the treatment prescribed by the nurse, and a letter later written by Corrigan to Dr Percy E. Moore, are strongly suggestive that the girl died of tuberculous meningitis, a disease that may cause persistent headache, neck stiffness, nausea and fatigue. It is not clear why the principal and Indian Agent declined to specify the cause of death, however it is possible that there may have been some feeling of liability or responsibility for inadequately treating the girl and for not informing the doctor, especially after the earlier death of Margaret B. due to TB.

The third child to die of TB during this thirteen-month period was Mary D. Though still young she was a few years older than the others, aged eleven when she was admitted in September of 1941. She, too, had come to St Joseph’s from God’s Lake. Her entrance examination notes that the chest x-rays taken prior to admittance were negative, and that there were no signs of TB at that point. However, it was reported that her mother was thought to have died of the disease. With the infection present in her home she certainly would have been exposed, and there was a possibility that she had acquired a latent infection.

The first sign of her illness is found in the quarterly return for the period ending June 30, 1942. She appears to have been absent from class for the entire three-month period, and was discharged as sick the following quarter, suggesting a very severe disorder. In this, Mary D. was likely sent to her home in God’s Lake, as the entry for the quarter ending December 31, 1942 noted that she “Was sent back to the Doctor, though she had been discharged on his advice.” She returned to St Joseph’s and must have recovered somewhat, as she managed to
attend classes on forty of the seventy days she was registered. A bout of influenza during the period January to March, 1943 kept her away from class for 38 days. 24

The memorandum of inquiry into Mary D.’s death provides some insight into the final period of her life. 25 She had fallen ill on May 17, 1943, and, as with the others, she was seen by the nurse and placed in the infirmary. In her case, though, Dr Corrigan saw her on the 24th and was able to indicate a course of treatment to the school personnel. According to Principal Trudeau, the doctor prescribed no medicines but simply directed that Mary D. be kept on bed rest until June 2, when she could be transported by canoe to the hospital at Norway House. From then until her death due to tubercular meningitis on June 11th she was under Corrigan’s care. She was twelve years old. 26

Less than two weeks later, on June 24th, Martha R., the last of the four girls, died. Here was another young girl from Cross Lake, who had been admitted to St Joseph’s in February of 1940 at the age of six. Interestingly, the quarterly returns attributed no sickness to her during the year and a half prior to her death, unusual given that she had TB. 27 She had first been ill on April 14th, and reported initially to the nurse. In her case, however, the doctor arrived the following day, and immediately prescribed bed-rest, but again specified no medicines. This in itself would not have been remarkable during these pre-antibiotic days, as tuberculosis was generally treated through rest, diet and, for some forms of the disease, surgical techniques. Martha R. saw Dr Corrigan again on May 24th when he returned to the school. By that point her condition had improved somewhat, however she took a turn for the worse on June 1st. 28 Three weeks later she died at the school of tubercular meningitis (with pulmonary TB contributing).

The quarterly returns hint at much more in the way of death and disease than just these four, and from them we can get a picture of a very unhealthy situation. 29 These girls were not the only ones to have active TB. In the quarter ending June 30, 1942, one student was sent home with TB. The following quarter another was discharged with TB, and several others discharged for no given reason. Their fate is unknown, however it seems unlikely that they received medical assistance upon their return home. Two other boys died of unknown causes over the summer holiday period in 1942. During the quarter ending March 31, 1943, all of the children were afflicted with influenza. Such epidemics had been known to trigger outbreaks of reactivated latent TB among those who were infected. 30 Finally, during the three-months ending June 30, five boys and eight girls were discharged for no given reason, several had operations, and a large number were listed as “sick.” Again, there is no evidence whether they recovered or not, nor of what their illness was. Any number of those discharged could have been ill with TB, as the policy in the Norway House Agency at the time was to send those suffering from that disease back to their homes, despite the possibility of infecting others and the absence of appropriate medical care. 31

To this point there had been no sign of conflict or controversy in the school records concerning these deaths. This changed with the death of Martha R. In the section of the memorandum of inquiry into her death filled out by Dr Corrigan, he showed obvious frustration with the staff of the school in their attention to his instructions. When asked whether they had taken all reasonable care with respect to the girl’s death and whether they had followed his instructions, he replied in the negative. 32 When asked to expand on this, the doctor explained that they had failed to carry out his order to have Martha R. placed on bed-rest for a period of six months to a year. Corrigan did note that he doubted that it would have made a difference had they followed his instructions, as he considered the meningeal form of TB to be “a [chance] and that it occurs even with the best of care.” 33 Prior to the development of anti-TB medications, meningeal tuberculosis was almost invariably fatal.
Evidently, this was not an isolated incident. In a letter written in July of 1943 to Dr Percy Moore, the acting Superintendent of Medical Services for the Department of Mines and Resources, Corrigan complained that Trudeau and his staff had failed to carry out orders for bed rest for other students at the school. More importantly, the doctor laid out two other broad failings of the school with respect to the health of the children. First, he had ordered that all students from communities other than Cross Lake appear at Norway House during the summer break in order to be x-rayed for TB. While the Island Lake students had travelled to the hospital, none from God’s Lake had appeared. As such, he was unable to determine who among them had the disease.

The second issue identified by Corrigan was overcrowding. It had long been understood by the medical community, and by the Department of Indian Affairs, that placing too many students in a school led to increased opportunities for spreading pulmonary TB should one or more students be infective with the disease. This was particularly so with respect to crowded conditions in the sleeping dormitories. Since 1892, the amount paid to the residential schools had been set according to the number of students enrolled during the term, and some principals argued that it did no harm to accept admission of infected children since the disease was already present and widespread in the schools. Nevertheless, there had long been school-specific guidelines in place for each residential school as to the upper limit of enrolment, based on the size of the sleeping quarters and the cubic footage of air available. Dr Corrigan noted that St Joseph’s was designed for eighty students, but that they had had one hundred enrolled during the previous year. In fact, the St Joseph’s quarterly returns for the period from January 1942 to June 1943 show an average enrolment of 99, with a variance between 96 and 104. Corrigan observed that in order to fit the surplus students in the dormitory, the beds had to touch side to side and head to foot, ideal circumstances for spreading the infection.

Corrigan’s recommendations suggest that the problem of TB in the Cross Lake school was substantial, that it was due in part to negligence, and that major changes to the school’s operations were required. For one, he asked that the students who had been identified as having TB in his incomplete survey not be allowed to return the following fall. Although this request may now seem obvious, as it would have prevented infection in the school, the situation was somewhat complex in 1943. Simply put, there was no space in the Norway House Hospital for long-term care of more than a few people with TB, and there were no funds to send them south to another TB hospital for treatment. The doctor’s order simply sent the victims back to their home communities, where they were liable to spread the disease to others.

Moreover, Corrigan implored Moore to immediately direct Principal Trudeau, through Indian Agent P. G. Lazenby, to limit the number of students to eighty. This was hardly a radical request as he was asking the Department only to enforce its own regulations. Similarly, he insisted that all students be given x-rays before entering the residential school. The fact that he did so “in order to protect [himself] and the Department,” is strong evidence that things were going particularly wrong, and that questions of liability might one day be raised. If Corrigan is to be believed, and there seems no reason not to believe him, significant numbers of children were contracting TB while at St Joseph’s. He wrote that: “I have brought over [to the hospital] from Cross Lake enough children whom I had x-rayed a year or two years ago, to know that many of them must have developed tuberculosis in the school during the first year.” His words echoed those of a predecessor at Norway House, Dr W. N. Turpel, who wrote in 1930 that: “Many of them remain for years and some of them get broken down in health in the schools. A yearly check up on them would enable one to weed out those likely to break down.”
Again, this was hardly a shocking demand. X-ray equipment had been installed at the Norway
House Hospital in 1931 or 1932 for just such a purpose, at the cost of $2,264.35. Indeed, Indian
affairs had required prospective residential school students to submit to a physical exam by a qualified doctor for several decades, and in recent years that order had been amended to include a chest x-ray. The doctor would subsequently fill out an entrance examination report, and would recommend either rejection or acceptance based on the child’s health. In practice this program was often ignored. Officials in Ottawa knew that many students gained entrance to residential schools without a legitimate exam, and many others were admitted with signed examinations of dubious quality (Milloy 1999:89). Each time that a circular was issued by Ottawa reminding church authorities that such examinations were required, replies immediately came back stating that it was impossible to comply with the directive. Often, Ottawa took a conciliatory approach and allowed the schools to make some other arrangement.  

Finally, Corrigan called for a ban on admitting children from Island Lake to either St Joseph’s or the United Church’s residential school in Norway House. His rationale for refusing them admittance was based on his perception of their lack of resistance to the disease. He noted: “the Island Lake people have very little immunity to tuberculosis and I do not believe they should be brought out and mixed with people who have practically 100% infection.” Again, on the face of it this is sound reasoning. This directive is similar to that of another of Corrigan’s predecessors at Norway House, Dr E. L. Stone, who wrote in 1925 that the isolated Island Lake Band was not “severely infected with tuberculosis,” and that the best policy would be to leave them alone until such time as it would be necessary to interact with them (1989:237-56). Despite Corrigan’s beliefs, however, it is not clear that the disease was all that rare at Island Lake at the time. In December of 1941, the Reverend Arthur McKim, the United Church missionary at Island Lake, commented in a letter to his supervisor, John Comrie, that “Many cases of T.B. die [at Island Lake] for lack of a little rest and nutritious food.” More directly, he observed that “two children were sent back [from the Norway House Residential School] for active T. B. who are around here now quite normal.”  

Ottawa accepted some, though apparently not all, of Corrigan’s recommendations, and passed them along to the Oblates, along with the doctor’s original letter. On July 13th R. A. Hoey informed Bishop Martin Lajeunesse that there would be no more than eighty pupils allowed in residence at St Joseph’s for the upcoming 1943-44 academic year. He also relayed the Department’s directive that no child was to be taken from Island Lake during that academic year. There had been six such students at the school as of March of 1942. In reply, Lajeunesse agreed to follow these regulations, stating that “We are more than anybody else interested in the physical welfare of the children and no doubt the Department will appreciate that since the last four years we have a registered nurse in permanence to take care of the health of the children.”

At the same time, the Bishop accused Corrigan of lying in his report. It is readily apparent that the Oblates held a different view as to the cause of the underlying health problems among the Indians of the Norway House Agency. They pointed to problems inherent in the administration of the schools and the provision of health care by Indian Health Services, both the responsibility of the federal government. With regard to overcrowding, Principal Trudeau argued (as many others had before him) that with eighty students the per capita grant was inadequate to run the school; with one hundred they were able to break even. Should the federal government increase the value of the grant, Trudeau argued, they would be able to maintain a healthy number of students rather than filling the dormitories to overcapacity.
A more telling criticism was that the health services provided by the federal government to the Indians living north of Lake Winnipeg were far from adequate. The lack of medical attention was a longstanding issue in the area. As early as April of 1922 the people of Cross Lake had petitioned Ottawa for the construction of a non-denominational hospital near the site of the school. In reply, A. F. MacKenzie stated that “The Department is maintaining a Hospital at Norway House for the benefit of the Indians in the district, it is considered that this institution furnishes ample opportunity for the Indians of Cross Lake Band who require Hospital treatment.” MacKenzie also noted that Cross Lake benefited from “frequent” visits by the M.D. stationed at the hospital.50 This policy remained in place in 1942, although the number of visits by Dr Corrigan was far from adequate for any of the reserves save Norway House.51

Lajeunesse’s comment was in keeping with ongoing criticisms expressed by both himself and Protestant officials in the Norway House Agency. Earlier, in August of 1941, he had lectured the Minister of Mines and Natural Resources, T. A. Crerar, on the nature of TB in the Norway House Agency. Noting that there were four thousand Indians living within the five reserves of the Agency, the bishop observed that they received no medical care for the disease.52 When any person was diagnosed with TB they were simply returned to their communities, “to die a miserable death after having spread the germs of his disease among his own people at home and neighbourhood.”

Rather than dispute the bishop’s general argument, Crerar replied: “I fully realize that there are many cases of tuberculosis among the 4,000 Indians of the Norway House Agency who are not receiving treatment.” 53 Still, he pointed weakly to the twenty-two Indians who were under treatment at the Norway House Hospital at the time as something of a success story, and held out hope that Indian Affairs might free up funds to expand the hospital, should they become available. Nevertheless, the number of TB beds in place at the hospital was so small as to be almost meaningless, and in fact capacity had only recently been increased from sixteen to twenty-four beds.54

Of those individuals concerned with the deaths of the four girls at St Joseph’s, only one appears not to have criticized the circumstances behind their occurrence. In each case save one the Indian Agent, P. G. Lazenby, signed off on the official inquiries without comment. In the case of Margaret B., he went further and stated “everything possible is being done at this school for the health, safety and welfare of the pupils,” a glowing recommendation given the doctor’s concerns.55 In light of the animosity between Corrigan and the Oblates, and the accusations being tossed against each other, it seems odd that Lazenby would not weigh in on the matter, particularly with the issue of potential liability in question. However, it is possible that the agent was indeed satisfied that everything had been done given the limited health resources available and the dynamics of travel in the region. Improved conditions would require something more substantial than tweaks to the practices of either church or hospital, and he may have been reticent to remind Ottawa that the fault lay with them.

A New Era

By the early 1940s the public health benefits so optimistically trumpeted in 1937 had yet to be extended to the north. Referring to the original goal of clearing accessible communities and schools of TB, T. A. Crerar wrote in October of 1941, “When this has been accomplished, and when more funds are available, it is the aim of the Department to extend this control campaign to the more remote areas.” 56 “This change in emphasis came, finally, towards the end of the decade. In 1945 jurisdiction over Indian Health Services was transferred from the
Indian Affairs Branch of the Department of Mines and Resources to the Department of National Health and Welfare. The net result of this transfer was an increased commitment to deal with tuberculosis among the Indian people (Waldram et al 2006:20). Sadly, the deaths of the four girls at St Joseph’s Residential School in 1942-43 came only a few years before sweeping improvements were made to the treatment of TB among the Indians of Manitoba. Within five years, two of the main contributing factors to their deaths, the inability to find the disease early in its course and the lack of available treatment beds, had been addressed. A third, the ongoing conflict between the goals of church and health officials, was bypassed, while improvements in TB treatment made the survival of even advanced cases a possibility.

Case finding was considered a key to providing effective treatment for TB, and potentially eliminating the disease from the Indian communities. Until the late 1940s, however, those in the northern part of Manitoba were largely bypassed by the surveys carried out by the province. As of the mid 1940s, Federal officials attributed the geographic limitations of their efforts to the “lack of regular and organized methods of transportation and communication in isolated and northern outposts, coupled with the nomadic habits of the natives.” The solution, they argued, would be to integrate “modern aircraft facilities ... into health services.”
This change came, finally, in 1948. Over the next two years most of the Indian people in Manitoba received chest x-rays for pulmonary TB, as even the most isolated communities were accessed by truck, boat or plane accompanying the annual visit of the treaty party. Many of these people had never been tested for TB before, and unsurprisingly the number of new cases found was high. In 1948, 9,393 were x-rayed, and 272, about 3%, were found to have active TB. The survey was not yet universal, however, and coverage varied between bands from approximately 15% to 90%.

The following year brought even more complete coverage. In 1949 most of Manitoba’s Indians, 16,479 in total, were examined for TB through a combination of stationary clinics, travelling clinics, and, in the vast majority of cases, surveys (Table 1). Bruce Noton, an x-ray technician who joined the northern leg of the TB survey, later described the route taken by the survey team as it meandered through the north, from The Pas to all of the major Indian communities, and, as predicted, air travel figured prominently (2000) (Figure 5). Over the course of the summer Noton’s party reached ten communities and x-rayed over 2,400 people.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>TB Case-finding in Manitoba for 1949</th>
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<tr>
<td></td>
<td>White</td>
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<tr>
<td>Stationary Clinics</td>
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<tr>
<td>Travelling Clinics</td>
<td>4,477</td>
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<td>Surveys</td>
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<tr>
<td>Hospital Admissions</td>
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<td>Total</td>
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</table>

In this second year of the province-wide survey, the number of new active cases among the Indians remained high. Of the 16,369 x-rayed on the survey, 248 active cases were found. This amounted to a rate of 1.5%, less than for 1948 but still twenty-five times the rate among non-Indians. As pre-existing cases were identified and removed for treatment over subsequent years, the rate of new TB cases to the total surveyed continued to drop. By 1950, only 0.7% of the 15,391 Indians surveyed, or one in 138, were found to have active TB.

These mass x-ray surveys, carried out annually on the reserve as part of the treaty process, served to limit the need for access to the schools by medical officers such as Corrigan, at least with respect to ascertaining TB status among the students. They also removed the issue of whether or not students were examined by medical doctors before entrance, since the students would be tested on their home reserves even before they were old enough to attend school. Further, they provided grounds for removal of tubercular students before they returned to school in the fall. Each of these had been a source of conflict between school and medical officials.

Not all who were identified could be given prompt treatment. As late as 1949 the Sanatorium Board of Manitoba noted that delays in hospitalization occurred occasionally, but were “unavoidable and mainly due to difficulties of transportation, ignorance and sometimes shortage of beds.” In fact, case-finding, through mass x-ray surveys, was only part of the solution. Overall, Indian Health Services was forced to tie the breadth of its surveys to the number of treatment beds that were available. As new TB facilities were opened, the surveys became more extensive, though as of 1947 there remained a “perpetual waiting list” in many parts of Canada.
In December of 1943 the Canadian Tuberculosis Association estimated that 100 TB beds were available for Manitoba’s Indians, a substantial deficit compared to the 480 beds that the organisation believed were required.\textsuperscript{67} This was perhaps an unrealistic goal in the short term, as in 1943 Indian Affairs Branch operated 14 departmental hospitals for Indians throughout the country, with a total bed capacity of only 540. All told, only 1,500 Indians were treated for TB in hospitals and sanatoria in 1943.\textsuperscript{68} That year, the newly purchased Dynevor Hospital was working at near full capacity, with an average occupancy of 47.1 patients (91.9%), but this was far from adequate for the needs of the Indian people of Manitoba, as determined by provincial officials.\textsuperscript{69} A total of 106 TB patients were admitted over the year: 69 from Manitoba, 35 from Ontario, and two others from Minnesota. Six others Indian patients were treated in the St Boniface Sanatorium, a facility for the treatment of tuberculosis among the province’s Catholic population. While better than it had been, this limited number of beds was far from adequate.

In 1945 options for Aboriginal TB treatment in northern Manitoba improved substantially with the creation of a second major TB hospital, complementing the earlier acquisition of Dynevor. In order to provide the much-needed beds the Department of National Health and Welfare purchased a redundant U.S. Armed Forces Hospital located in The Pas, to the west of Norway House, and renamed it Clearwater Hospital (Figure 2). Once again, arrangements were made with the Sanatorium Board of Manitoba to run the hospital. Initially, Clearwater had a capacity of 75 beds, however plans called for the enlargement of this and other existing facilities to provide approximately 125 additional beds.\textsuperscript{70}

In 1947 the federal government transferred a Canadian military hospital in southern Manitoba to the Department of National Health and Welfare for the use of Aboriginal patients. After its first full year of operation the Brandon (Assiniboine) Sanatorium had a maximum occupancy of 255 beds, and during 1948 it provided 75,697 total patient days of treatment. 265 patients were admitted: 248 treaty Indians, three Inuit, ten Métis and four non-Aboriginal people.\textsuperscript{71} Moreover, Clearwater’s capacity had been increased following renovations, and in 1948 there were 104 admissions, 81 of whom were treaty Indians.\textsuperscript{72} By 1949 there were 750 TB beds for non-Natives in Manitoba, and the three main TB treatment facilities for Indians, Dynevor (50 beds), Brandon (250) and Clearwater (160) together provided a total of 460 beds.\textsuperscript{73} Case finding and treatment for Indians in Manitoba were finally on a par with that for non-Native people in the province.

The greater availability of TB beds proved a critical turning point in TB treatment in Manitoba, as the disease was caught, and treated, earlier than before. Earlier treatment meant a higher success rate and fewer casualties. This was critical for another reason. According to the Sanatorium Board of Manitoba, once diagnosed and denied treatment at that time, the Indian patient might not ever be admitted, “partly because he is likely to be returned to the reserve, which may be, and often is, difficult of access and partly because, unlike the average white patient, further persuasion or compulsion is commonly required to bring him to the hospital when a bed is finally available.”\textsuperscript{74} There was an astounding improvement in this area between the early 1930s and the late 1940s. In 1933 only 10.2% of Manitoba Indian TB deaths occurred in an institution. The vast majority of TB-positive Indian people in the province, then, were not getting treatment and were dying at home, able to pass the disease on to others (Walton 1934: 10). From a public health perspective this was a crucial problem. As late as 1943, thirty-one (40%) of the patients admitted to Dynevor for pulmonary TB were in a far advanced state and another eleven entered in a “hopeless” condition.\textsuperscript{75} Seven of the latter died. By 1948 almost half of Manitoba Indian TB deaths were occurring in a sanatorium, and 71 of the 125 Indian deaths were in a hospital of some sort, indicating increased access to
treatment (Table 2). This meant earlier treatment in the course of the disease, usually before it had taken hold in a fatal form.

<table>
<thead>
<tr>
<th></th>
<th>Whites</th>
<th>Indians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths occurring in Sanatoria</td>
<td>98</td>
<td>57</td>
</tr>
<tr>
<td>Deaths occurring in General Hospitals</td>
<td>21</td>
<td>13</td>
</tr>
<tr>
<td>Deaths occurring in Mental Hospitals</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Deaths occurring at Home</td>
<td>14</td>
<td>54</td>
</tr>
<tr>
<td>Total</td>
<td>146</td>
<td>125</td>
</tr>
</tbody>
</table>

In addition, new advances in chemotherapy were available by the late 1940s, providing more hope for surviving the more severe forms of TB. Streptomycin, which had been introduced into the province in 1947, was used extensively for the first time the following year in all Manitoba sanatoria. By 1949 this antibiotic had become a regular therapy at both Brandon and Clearwater, and the newly-introduced para-aminosalicylic acid (PAS) was used on ten patients at Brandon. While initially used as an adjunct to surgical techniques, the new anti-TB drugs were soon viewed as successful therapies in their own right, and it was found that cases once considered hopeless would now respond favourably to treatment. In 1950 the Sanatorium Board of Manitoba observed that, with respect to tuberculous meningitis, five out of six patients diagnosed that year with that form of TB had survived. In an earlier era most, if not all, would have died quickly. In turn, these improvements had a positive effect on the death rate. In 1935 the Indian TB death rate was 1,258 per 100,000; by 1949 it was less than half, at 612 (Stewart 1992:167).

Despite the inroads being made into TB mortality among Manitoba’s Indian people starting in the 1940s, it is important to note that not all parties look back fondly on this era of increased government involvement. Those from the medical community have portrayed the case-finding and treatment programmes as a success, pointing to declining TB infection and mortality, and rising populations, as evidence of a sound policy (Ross 1967, Stewart 1999:96, Wherrett 1977). Even where standard medical treatments were of questionable efficacy for people with advanced disease, as they were especially prior to the development of streptomycin and PAS, simply removing those with active infections from schools or reserves, it was argued, helped to combat the disease. Thus, Dr David B. Stewart, the son of the pioneering Manitoba TB physician, David A. Stewart, later defended the use of public health laws that gave the Royal Canadian Mounted Police the legal basis to arrest reluctant Indian TB victims, using force if necessary, and remand them to the hospitals, at a physician’s request. Stewart wrote: “In retrospect this massive transfer of people from their communities may seem to have been rather drastic; but it was probably the only way to break the vicious cycle of infection and re-infection” (1992:167).

Stewart’s justification speaks to a much darker perspective on this era of mass TB treatment, one shared by many Aboriginal people across Canada, but especially in northern Manitoba. Elsewhere Stewart noted that the efforts of the medical community, though effective, had been denounced by some as “being both excessive and draconian” (1999:96). In his study of the treatment of TB among the Inuit, Grygier documented the heavy-handed approach taken by the government following 1945, and its effect on those with TB and on their communities (1994). Those Inuit who were found to be TB positive were immediately removed from their
communities and sent south to distant sanatoria. In many cases, their community never saw them again, and for these patients conditions in culturally-foreign institutions proved very harsh. A similar process occurred among the Indians living in northern Manitoba, especially during the early years following the construction of the Clearwater facility when survival was uncertain. Stories have recently begun to emerge about harsh treatment and undocumented deaths at the hospital during the 1940s and 50s, echoing complaints raised by band officials during its early years (McKinley 1998). Ironically, treatment that has been seen in a highly positive light by the medical community, and is now portrayed as a key to preserving the lives of the Indians of northern Manitoba, has today emerged as a political issue portrayed by some in the Native community as an act of genocide.

Conclusion
In the early 1940s four young girls died of TB at St Joseph’s Residential School, on the Cross Lake reserve to the north of Lake Winnipeg. As much as they were victims of the disease, they were also victims of their times and of where they lived. The fact that they lived in the northern part of Manitoba, isolated and far from the settlement frontier, ensured that they would not receive the care that might have allowed them to live, for their sickness was not considered a threat to the white population of the province. Had they been living to the south of the lake, their fate might very well have been different.

Likewise, the fact that they fell ill during the first few years of the 1940s, and not during the last few years of the decade, placed them in jeopardy. Despite a renewed commitment on the part of the Canadian government in 1937 to root out the disease on the reserves and in the schools, that commitment had yet to be extended to all of the Indian people. Had their illnesses arisen just six or seven years later, when Canada began to make good on its obligations, they might have survived.

These were deaths that had their roots in policies that had been established long before any of the children had been born; their ends were echoes of the deaths of children who had succumbed to TB in the last decade of the nineteenth century, or the first decade of the twentieth. Although each side blamed the other, these children were almost certainly failed by the combined actions, or inactions, of the principal, the Canadian government and the doctor. The inability of the school to provide a healthy environment for the students, one that was free of disease, and the failure of the agents of the federal government to catch their infection early, and to treat them before their sickness became fatal, contributed greatly to their demise. Sadly, it would only be a few years until new policies were put in place, and such deaths became rare indeed.

Acknowledgements
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References


Notes

1 W. M. Graham to Duncan Campbell Scott, Deputy Superintendent General of Indian Affairs, Regina, February 10, 1925 (Library and Archives Canada (Hereafter LAC) RG 10 Volume 6016, File 1-1-13 Part 1).

2 Mainly Roman Catholic, Anglican, Presbyterian (later United Church).
3 LAC RG 10, Volume 3855, File 79963 “Manitoba – Dr. G. Orton’s report on the deleterious effects of civilization on Indians and subsequent efforts to ventilate schools as a protection against Tuberculosis, 1891-1895”
6 Dominion of Canada Annual Report of the Department of Indian Affairs for the Year ended March 31 1935, p. 10.
7 LAC RG 29 Volume 1225, File 311, Dr. D. A. Stewart to Premier John Bracken, Nov. 14 1934, p. 5.
9 LAC RG 29 Volume 1225, File 311, Stewart to Bracken, Nov. 14, 1934, p. 5.
11 Dominion of Canada, Annual Report of the Department of Indian Affairs for the Year ended March 31 1928, p.9.
13 Canada Department of Mines and Resources Report of Indian Affairs Branch for the Fiscal Year Ended March 31, 1940, p. 185.
14 Canada Department of Mines and Resources Hon. T.A. Crerar, Minister, Charles Camsell, Deputy Minister Report of Indian Affairs Branch for the Fiscal Year ended March 31, 1938, p. 8.
15 The school had been established to accommodate the education of the Roman Catholic children of five reserves in the Norway House Agency, including Norway House, Cross Lake, Oxford House, God’s Lake and Island Lake.
18 These are the documents kept by the principal of the school and filed every three months. They list the names of the students enrolled at the residential school during the quarter, their attendance, reasons for not being in class, and other pertinent information. They were designed to enable Indian Affairs to determine the correct compensation for the schools, based on student attendance.
21 LAC RG 10 Volume 6260 File 577-1. Doctor Cameron Corrigan to Dr. Percy E. Moore, Acting Superintendent of Medical Services, Department of Mines and Resources, Norway House, July 6, 1943
30 As happened in the winter of 1940-41, when a widespread influenza epidemic killed many of the remote Indians, and “also resulted in lighting up many latent cases of tuberculosis, causing, a sharp increase in deaths from this disease.” (Canada Department of Mines and Resources Report of Indian Affairs Branch for the Fiscal Year ended March 31, 1941, p. 164).
31 NAC RG 10 Volume 6260 File 577-1 part 2 Martin Lajeunesse to T. A. Crerar, The Pas, August 1, 1941.
34 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Percy E. Moore, Norway House, July 6, 1943.
35 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Percy E. Moore, Norway House, July 6, 1943.
37 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Moore, Norway House, July 6, 1943.
38 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Moore, Norway House, July 6, 1943.
39 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Moore, Norway House, July 6, 1943.
40 The issue of liability with respect to the death of residential school pupils may have first been raised in 1935, in conjunction with the directive that all future deaths be followed immediately by an inquiry in order to protect the school and department (LAC RG 10 Volume 6016, File 1-1-23 Part 1, A. F. MacKenzie, Secretary, to Indian Agents and Principals of Indian residential schools, Ottawa, October 17, 1935).
41 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Moore, Norway House, July 6, 1943.
42 LAC RG 10 Volume 6016, File 1-1-13 Part 1, Dr. W. N. Turpel to Unknown, Norway House, May 20, 1930. In 1896 Deputy Superintendent-General of Indian Affairs, Hayter Reed, observed that: “It is remarkable that many children apparently healthy on their admission to the different schools, are affected with tuberculosis” (LAC RG 10 Volume 3957, File 140, 754-1, Hayter Reed to unknown [A. E. Forget?], Ottawa, 24 April, 1896).
43 Dominion of Canada Annual Report of the Department of Indian Affairs for the Year Ended March 31 1932, p. 77.
44 See, for instance, the letter from Indian Agent Harold Laird to Russell Ferrier, in which Laird stated “I think that those in charge at the Missions are capable of judging whether children seeking admission to Residential Schools are in ordinary good health, and that they would refuse to admit such as might endanger the well-being of those in the schools.” See also Ferrier’s reply to the affirmative (LAC RG 10 Vol. 6016 File 1-1-13, Part 1, Harold Laird to Russell T. Ferrier, Grouard, Alberta, March 9, 1925; Ferrier to Laird, Ottawa, 16 March, 1925).
45 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Moore, Norway House, July 6, 1943.
47 LAC RG 10 Volume 6260 File 577-1 part 2, R. A. Hoey to Bishop Martin Lajeunesse, Ottawa, July 13, 1943.
49 LAC RG 10 Volume 6260 File 577-1 part 2, Corrigan to Moore, Norway House, July 6, 1943.
50 LAC RG 10 Volume 4072 File 438,382, Chief Peter Ross (Cross Lake) and members of the Cross Lake band to Duncan Campbell Scott, Superintendent General of Indian Affairs, Cross Lake, 3 April, 1922; A. F. MacKenzie to Ross, Ottawa, April 28, 1922.
51 On the lack of health care for the Island Lake Indians see, for example: United Church Archives, Winnipeg. Island Lake Charge File, Folder 2: Island Lake Correspondence 1940 – 1942, Rev. Arthur McKim to John A. Comrie Island Lake Mission, December 30, 1941; William Neufield to Cormie, Island Lake Mission, September 17, 1943; Report to the Ministers of the United Church (Elgin Presbytery) from McKim, January 25, 1944.
52 LAC RG 10 Volume 6260 File 577-1 part 2, Lajeunesse to T. A. Crerar, Minister of Mines and Natural Resources, The Pas, August 1, 1941. Lajeunesse asked that his order be allowed to establish a sanatorium in a church building at Norway House. This was rejected by Crerar.
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54 Canada Department of Mines and Resources Report of Indian Affairs Branch for the Fiscal Year ended March 31, 1942, p. 165.
56 LAC RG 10 Volume 6260 File 577-1, Part 2, T. A. Crerar to Martin Lejeunisse, Ottawa, 8 October, 1941.
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59 Canada Department of Mines and Resources Report of Indian Affairs Branch for the Fiscal Year ended March 31, 1947, p. 20.
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63 Tuberculosis Control in Manitoba, The Annual Report of the Sanatorium Board of Manitoba for 1949, p. 28.
64 Tuberculosis Control in Manitoba, The Annual Report of the Sanatorium Board of Manitoba for 1950, p. 28.
66 Canada Department of Mines and Resources Report of Indian Affairs Branch for the Fiscal Year ended March 31, 1947, p. 22.
68 Canada Department of Mines and Resources Report of Indian Affairs Branch for the Fiscal Year Ended March 31, 1943, p. 8.
69 The Sanatorium Board of Manitoba, Report for 1943 pp. 15, 27.
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74 The Sanatorium Board of Manitoba, Report for 1944, p. 20.
75 The Sanatorium Board of Manitoba, Report for 1943 pp. 15.
78 Tuberculosis Control in Manitoba, The Annual Report of the Sanatorium Board of Manitoba for 1948, pp. 12, 22.
Chapter 11
“She was weakly for a long time and the consumption set in”: Using Parish Records to Explore Disease Patterns and Causes of Death In a First Nations Community
Christianne V. Stephens

In *The History of the Ojebway Indians* (1861), the Methodist missionary Peter Jones paints a somber portrait of the pervasiveness of TB among indigenous groups in Canada and the ravaging physical toll the disease bore on its victims:

The Indians die of inflammation of the lungs and consumption more frequently than any other disease...Many of them linger, but a short time; others gradually waste away till they are reduced to skeletons, and at length, the little spark of life quits the enfeebled and emaciated frame (1861:142).

The biological legacy of tuberculosis in the Americas and its devastating impact on the health of First Nations and Inuit populations has been well-documented (Herring and Hoppa 1999, Waldram *et al.* 1995  Young 1994). Historical epidemiologists have long recognized the importance of church records to the study of population health. Qualitative and quantitative cause of death data gleaned from parish sources can elucidate demographic shifts, disease patterns and periods of ‘crisis mortality’. Parish information is also an index of the social, political, and economic forces which both allowed diseases to thrive, and laid the foundations for contemporary health problems (Farmer 1992, Moffat and Herring 1999, Nakamura *et al.*, 1991, Waldram *et al.*, 1995, Young 1994).

![Map of Walpole Island First Nation](image_url)

**Figure 1** Map of Walpole Island First Nation. From *Minishenhying Anishnaabe-aki: Walpole Island: The Soul of Indian Territory* (1987). Reprinted with the permission of the Nin Da Waab Jig Walpole Island Heritage Centre.
This article examines patterns of disease and causes of death in a historic parish population at the Walpole Island First Nation, a Native community located in Southwestern Ontario, Canada (Fig. 1). Also known as Bkejwanong, which means “where the waters divide” in Ojibwe, Walpole Island is the ancestral homeland of the Ojibwe, Odawa, and Potawatomi people.1 Mortality data obtained from Anglican parish registers and clergy reports are used to evaluate disease events. Like other Aboriginal populations, members of the Walpole Island Anglican population suffered from a spectrum of infectious diseases and health conditions precipitated by socioeconomic pressures experienced by the community during the 19th century. Framing quantitative and qualitative mortality data within a ‘syndemics’ model clarifies how concomitant and successive disease episodes increased the disease burden of the local population. Employing this theoretical approach also demonstrates the utility of integrative and holistic epidemiological frameworks for evaluating the constellation of variables that work synergistically to create ‘populations-at-risk’ and trigger health crises.

The analysis of mortality data from parish records

The data for this study were derived from the parish records, semi-annual reports and personal correspondence of the Reverend Andrew Jamieson, an Anglican missionary who was stationed at Walpole Island during the 19th century. Vital events (births, baptisms, marriages, and burials) for the years 1850-1885 were transcribed from the parish registers of St. John’s Anglican Church, Walpole Island to a database for analysis. Obituary entries included the name of the deceased, parents’ names (in the case of child deaths), age-at-death, and date of death. Of the 262 burials recorded, over half (56%) specified cause of death. The analysis for this study represents one piece of a larger health history project being conducted by the author in the community.

Parish records represent a potentially powerful source of information regarding issues of historical Aboriginal demography (Herring 1992, 1994, Hoppa 1998). Nonetheless, the extrapolation of health trends from historical sources is confounded by a number of factors. Small sample size, under-reporting, and contingencies that impede the expedient and consistent documentation of vital events all act to potentially bias the historical record (Drake 1974, Levine 1976, Lee 1977, Willigan and Lynch 1982, Wrigley 1977). Methods for testing the suitability of historical records, such as those suggested by Drake (1974:47-63), recommend a minimum figure of 100 recorded vital events and other standard numerical guidelines for evaluating parish records. However, these standards are inappropriate for historic Aboriginal communities which would have encompassed only a few hundred individuals, and whose socio-cultural and geographical contexts would pose a number of unique challenges to the recording of births, marriages and deaths (Hoppa 1998). Given that traditional approaches to the analysis of historical data cannot be used exclusively, and a direct evaluation of the parish records is not possible, the validity of the records was assessed indirectly by the relative accuracy and consistency with which they were recorded (e.g. Hoppa 1998). A cross-comparison between the Reverend Andrew Jamieson’s missionary records, reports to the Society for the Propagation of the Gospel in Foreign Parts2 (VPCMA) and parish records for St. John’s Anglican Church for the years 1850-1885 was conducted for the purpose of verifying the consistency of recorded variables. Historical, demographic and health data were also cross-referenced with information contained in contemporaneous local Indian Agents reports (Canada 1864-1990).

Barber and Berdan’s protocol for source analysis3 (1998:148-177) was used to evaluate the uniformity and historical accuracy of written sources. Andrew Jamieson’s thirty-five year
term as Walpole Island’s Anglican Minister is the reason for the high levels of homogeneity and consistency in the documentation of vital events. The credibility of Jamieson’s records is strengthened by his active involvement in community affairs. He learned the Ojibwe language and often fulfilled the role of intermediary in meetings between government officials and community leaders. Jamieson and his wife also provided health care to local residents. The dual role of missionary/medicine man was commonly fulfilled by clergymen assigned to Native communities in the 18th and 19th century (Graham 1975). The fact that most missionaries lacked formal medical training has raised questions regarding the accuracy of cause of death determinations recorded in parish sources. However, as Moffat and Herring have argued, the practice of diagnosis is “perilous at any time, regardless of the social and temporal context, or whether a trained physician was present in the community” (1999:1824). Narrative and numerical mortality data were grouped according to cause of death categories. Following Moffat and Herring (1999:1824), quantitative data were organized into the broad categories of infectious and non-infectious diseases advocated by McKeown (1976). Overall, the church records represent an appropriate and valid source of data regarding 19th century mortality in the Walpole Island community. As the objective of this study is to gain a general overview of patterns of disease and the social contexts of disease events, the small size of the historic parish population neither impedes nor compromises investigation of the biocultural phenomena that came to shape community health experiences.

Evidence for tuberculosis

Qualitative data

TB deaths were reported by the Reverend Andrew Jamieson in several of his professional and personal correspondence. In his report to the Lord Bishop of Huron, Jamieson writes:

Our junior chief Warden James Naudio also died at 30 years old. He was sober and industrious. Given the first prize for the best canoe at the Agricultural Show. He died two weeks later of consumption...I feel his loss very much (VPCMA, Jamieson file: 29 December 1874).

The clergyman reports on the death of a devoted parishioner in a letter written to the Reverend Thomas W. Bullock, of the Society for the Propagation of the Gospel in Foreign Parts:

Yesterday, I called upon one of our most devoted Indian women - for many years she has been an earnest and faithful disciple. About 50 years of age, far gone with consumption. I found her in a very weakly state, but glad and thankful to see me (VPCMA, Jamieson file: 9 June 1877).

To Mrs. Gibb, a church benefactor, he writes:

Recently, we met with a great loss with the death of one of our most promising Indians, industrious, intelligent and working member of the church. For several years, he was one of my best men, he fell victim to consumption (VPCMA, Jamieson file: 4 August 1884).

In a report to the Lord Bishop of Huron dated 29 June 1881, Jamieson mentions the death of a young choir member:

I am sorry to say that we are to lose one of our most valuable members of our choir. She is a young woman of about 24 years of age. She has been very ill for some time past
dying of consumption, that great enemy of the Indian. Her life on earth shall soon be ended (VPCMA, Jamieson file: 29 June 1881).

It is possible that one of Jamieson’s family members may have succumbed to tuberculosis. The clergyman refers to the “declining state” (a common euphemism for TB) and ultimate death of his first wife, Lois, in 1869 (VPCMA, Jamieson file: letter to Mr. Viday, date unknown).

Quantitative data

Percentages of total deaths with causes (Table 1) suggest that 61% of deaths were the result of airborne diseases, primarily diphtheria, tuberculosis and whooping cough. Other airborne diseases include croup, measles and smallpox. Waterborne diseases (cholera and dysentery) accounted for eight percent of deaths, while non-specific causes of death, such as diarrhea and various “fevers” claimed the lives of 20% of the parish population (predominantly infants and children). Causes of death classified under the category of “Other” accounted for 11% of deaths and include death from accidents, exposure, heart disease, intemperance, jaundice, paralysis and sunstroke.

Table 1  Walpole Island Anglican Parish population causes of death, 1850-1885.

<table>
<thead>
<tr>
<th>Cause-of-Death Categories</th>
<th>Number of deaths</th>
<th>Percentage (%) of total deaths with causes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Air-borne diseases</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TB (Consumption)</td>
<td>54</td>
<td>36.7</td>
</tr>
<tr>
<td>Probable TB cases*</td>
<td>8</td>
<td>5.4</td>
</tr>
<tr>
<td>Diphtheria</td>
<td>7</td>
<td>4.8</td>
</tr>
<tr>
<td>Whooping cough</td>
<td>13</td>
<td>8.9</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>5.4</td>
</tr>
<tr>
<td>Total</td>
<td>90</td>
<td>61.2</td>
</tr>
<tr>
<td><strong>Water-borne diseases</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cholera</td>
<td>2</td>
<td>1.4</td>
</tr>
<tr>
<td>Dysentery</td>
<td>10</td>
<td>6.8</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>8.2</td>
</tr>
<tr>
<td><strong>Non-specific</strong></td>
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<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td>13</td>
<td>8.8</td>
</tr>
<tr>
<td>Various fevers</td>
<td>16</td>
<td>10.9</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>19.7</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>16</td>
<td>10.9</td>
</tr>
</tbody>
</table>

Statistical break-down of total airborne diseases with causes (n=90) suggests that tuberculosis may have accounted for over half of the deaths (69%) from communicable diseases, while whooping cough (14%), diphtheria (8%) and other airborne diseases (9%) contributed to a relatively smaller number of deaths (Fig. 2).
Figure 2  Break-Down Of Total Deaths From Airborne Diseases With Causes [N=90]
By Cause Of Death Category.
* includes probable deaths from TB

Analysis of TB deaths by age category (Table 2) reveals that an appreciable number of young adults died from airborne diseases. The highest percentages of total deaths with causes from TB were observed in the 15-29 age group (82%) and the 30-44 age category (75%). Unlike other age categories where a number of airborne diseases contributed to overall mortality, all of the deaths in the 15-29 age group were from TB. Given the problems of under-reporting and small sample size, these percentages must be interpreted with extreme caution. The fact that the fewest number of deaths recorded by age group (excluding deaths where age is not specified) are those in the <1 age category (the population at greatest risk) is evidence of the under-reporting of infant deaths. Other factors may contribute to the seemingly ‘high’ numbers of deaths in the 15-29 age category. This group has a high percentage of cause of death determinations recorded in the registers (in comparison to other age groups) which may give the illusion of high mortality. Furthermore, the large number of TB deaths may simply reflect the fact that this age group represents a large population at risk of dying. Exploring the potential epidemiological significance of these values would necessitate a thorough investigation of possible biological, ecological and/or social variables that may have put individuals of this age group at greater risk of contracting and dying from TB. Other important analyses, such as the sex-distribution of mortality are further confounded by issues of language.  

Table 2  Age distribution of deaths from all airborne diseases and TB, Walpole Island Anglican parish population, 1850-1885.
* includes probable deaths from TB

<table>
<thead>
<tr>
<th>Age Category (in years)</th>
<th>Total deaths with causes</th>
<th>Number of deaths from airborne diseases</th>
<th>Percentage (%) of deaths with causes from airborne diseases</th>
<th>Number of deaths from TB*</th>
<th>Percentage (%) of deaths with causes from TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1</td>
<td>13</td>
<td>5</td>
<td>38.5</td>
<td>2</td>
<td>15.4</td>
</tr>
<tr>
<td>1-14</td>
<td>57</td>
<td>31</td>
<td>54.4</td>
<td>12</td>
<td>21.1</td>
</tr>
<tr>
<td>15-29</td>
<td>27</td>
<td>22</td>
<td>81.5</td>
<td>22</td>
<td>81.5</td>
</tr>
<tr>
<td>30-44</td>
<td>20</td>
<td>15</td>
<td>75.0</td>
<td>13</td>
<td>65.0</td>
</tr>
<tr>
<td>45+</td>
<td>17</td>
<td>10</td>
<td>58.9</td>
<td>9</td>
<td>52.9</td>
</tr>
<tr>
<td>Age not specified</td>
<td>13</td>
<td>7</td>
<td>53.8</td>
<td>4</td>
<td>30.8</td>
</tr>
</tbody>
</table>

whooping cough 14%
diphtheria 8%
TB 69%
Study of mortality seasonality reveals a noticeable peak in deaths during the late-summer and fall and a minor peak in deaths from airborne diseases during the winter months. The majority of deaths (over 70%) occurred between September and November and were comprised mostly of individuals 18 years of age and under who perished from non-specific causes of death (fevers and diarrhea) or waterborne diseases. This trend is also observed in the late-summer months. Jamieson attributed deaths from “fevers” during the late summer and fall to the wetland ecology of the island, which he believed was conducive to the spread of vectorborne (e.g., malaria) and waterborne diseases (cholera, dysentery). Mortality from airborne diseases (including tuberculosis) was consistently high throughout the year (accounting for more than 50% of deaths with causes recorded), although it appears to peak during the winter and early spring. Herring and Hoppa (1999) have identified a similar, statistically significant pattern of mortality seasonality among the James Bay Cree at Moose Factory. They conclude that a peak in summer deaths reflects a higher frequency of infectious disease outbreaks (due to increased population density and the introduction of pathogens through long-distance summer trade to the coast), while a weaker winter peak suggests a significant excess of tuberculosis-related deaths clustered in the winter months, relative to all other causes (Herring and Hoppa 1999, Hoppa 1998:180). The paucity of comparative data hinders a comprehensive analysis of whether the Walpole Island parish population’s health trends are similar to or different from other segments of the Walpole Island community and surrounding Native and non-Native populations. This fact alone underscores the pressing need for more research on the relationship between morbidity, mortality and social change within and between Southwestern Ontario communities.

Discussion

TB at the national level

Tuberculosis mortality on Walpole Island mirrors trends for First Nations communities across Canada throughout the 19th and 20th centuries. The dwindling Aboriginal population was attributed to “the presence of tuberculosis and kindred scrofula, aggravated by the conditions attending the earlier stages of transition from aboriginal to the civilized environment” (Canada 1905:20). Many government officials and medical personnel adopted a ‘racial paradigm’ when interpreting the incidence and prevalence of tuberculosis in Native communities. TB was perceived as a “racial trait” and an inherent feature of “Indian-ness” (Moffat and Herring 1999:1828). The disease was also described as being “sown in the constitutions” of young Indian children, “owing partly to insufficient diet, and partly to exposure to all kinds of weather” (Jones 1861:142). More often than not, tuberculosis was seen as the genetic legacy of an evolutionary past that would eventually contribute to the extinction of Aboriginal peoples in North America (Waldrum et al. 1995:262-269).

Although there was clear recognition that poverty, deprivation and crowded living conditions facilitated the spread of TB, blame for these conditions and the poor health outcomes that flowed from them was often ascribed to Native people themselves (Moffat and Herring 1999:1829). Living in ‘wigwams’ rather than ‘Western-style homes’ and leading a ‘traditional lifestyle’ were often cited as the causes for high rates of TB in Aboriginal communities (Stephens 2004:126-140). Health problems were often attributed to the ineptitude of Indian mothers who were viewed as “ignorant of the diseases common to children and of the proper treatment of them” (Jones 1861:143). Arguments couched in biological determinism and
negative cultural stereotypes precluded discussion of the ‘ultimate’ causes of disease, which evolved from ecological, social and economic conditions brought on by national policies and a rapidly changing economy (Waldram et al. 1995, Stephens 2004:154-157).

‘Syndemics’ and their impact on community health

Tuberculosis mortality represents only one dimension of the parish population’s health profile. Charting epidemiological trends necessitates looking beyond the history of a single disease to patterns of diseases which reveal the impact of multiple illness episodes on the biological constitution of the affected population. Syndemics occur when health-related problems “cluster by person, place, or time” (Milstein 2001:2). The term ‘syndemic’ describes the process by which two or more epidemics (notable increases in the rate of specific diseases in a population) interact synergistically to contribute to the excess disease burden in a population (Homer and Milstein 2002, Singer and Clair 2003). The biochemical changes produced by one pathogen contribute directly to the harmful impact of a second pathogen, which leads to a decrease in the functioning of the body’s immune system and increased susceptibility to disease (Singer and Clair 2003:425). 6

Patterns of mortality observed in the Anglican parish population over time suggest that syndemics modeled health patterns in the wider Walpole Island community. Most striking is the concurrence of deaths from tuberculosis and other airborne infectious diseases like measles, smallpox and whooping cough. The qualitative data corroborate the occurrence of concomitant epidemics. Jamieson describes an outbreak of smallpox in the year 1859:

The measles had been in the neighborhood for a month or six weeks before, and being of a very mild form caused no uneasiness. When the first person was seized with smallpox it was thought simply to be a lighter form of the illness [measles]...and thus breathing the bad air for hours, together in the crowded wigwam they inhaled infection and carried it to their house (VPCMA, Jamieson file: Report to the Lord Bishop of Huron, 1862).

A smallpox epidemic that struck the community ten years earlier (in 1849) was also preceded by a major disease outbreak. Duncan writes that “a serious blow was sustained by the mission in 1847 when an epidemic brought death to many” (1936:79). Jamieson reports that “chills, fever and ague ha[d] been common” and that children were afflicted with “bowel complaints, whooping cough and worms” (POA, Bishop Strachan Papers: 21 October 1847). Those suffering from the after-effects of illness were at higher risk of being infected by other diseases. Describing the death of the young woman, Petewewo, Jamieson writes, “she was weakly for a long time and the consumption set in—a disease that carries off many Indians… ” (VPCMA, Jamieson file: Report to the Lord Bishop of Huron, 1 July 1876). Alexander McKelvey (local Indian Agent to Walpole Island, 1883-1902) discusses how those suffering from influenza were more susceptible to contracting other diseases:

Owing to the prevalence of influenza, the Chippewas7 have not held their own this year. Many of the old people and weakly ones after having had the influenza were later taken with other diseases, and died in a very short time (Canada 1890).

Patterns of mortality for years with the highest recorded number of deaths (1873, 1874, 1880 and 1881) also provide evidence for the occurrence of concomitant and successive disease episodes. The year 1873 exemplifies syndemics in action: during this time period, concurrent outbreaks of consumption, whooping cough, and dysentery claimed the lives of several children in the parish population.
Recognizing the cumulative biological impacts of multiple disease burdens is one part of the disease equation. As Milstein argues, “preventing a syndemic requires not only preventing or controlling each [individual] disease, but preventing the forces that tie these diseases together” (2001:2). Understanding the political ecology of human biology entails critical analysis of the converging global-local histories, webs of social relations and politico-economic forces that affect human health (Goodman and Leatherman 1998). Relations of power influence ‘local biologies’ in specific ways and determine the differential distribution of health risks (Leatherman and Thomas 2001:117). At Walpole Island, disease events and health outcomes were influenced by historical contingencies and social pressures evolving from unequal power relations, competing political and economic interests, and decreased access to land and resources.

**Historical context: Land cessions, treaty-making and the political ecology of Walpole Island**

The defeat of the French in the Seven Years War (1756-63) led to the Royal Proclamation of 1763 which declared all lands west of the thirteen colonies as Indian lands. This proclamation stood as an affirmation by the British Crown to protect Native territory and interests from the exploitation of white settlers. Between 1790 and 1827, over four million acres of land in present-day Ontario were surrendered to the British Crown through land cessions (Nin Da Waab Jig 1987). Land treaties changed the physical landscape of what was to become the Dominion of Canada and heralded a new stage of Native-European relations. The so-called ‘Indian Problem’ evolved from two major quandaries challenging colonial administrators in North America—Native populations that did not conform to the lifestyle, subsistence economy and spirituality of Euro-Canadians, and the growing need for a larger land base to accommodate the influx of white settlers. The primary objective of government initiatives was to assimilate Native peoples “until there [was] not a single Indian in Canada that ha[d] not been absorbed” (Canada 1920). Missionaries and Indian agents were dispatched to Native communities: the former to educate and proselytize, the latter to ensure that local residents adopted agricultural practices and remained within the prescribed ‘boundaries’ of their reserves. The social welfare of Walpole Island residents was drastically affected by changes and circumstances emerging from the assimilation policies of the nineteenth century. These included land cessions and the appropriation of land; changes to the First Nation’s (government-designated) ‘political identity’; transition to a predominantly agricultural economy; and the Government’s failure to provide adequate medical care to First Nations communities.

**Land cessions and the creation of ‘Indian reserves’**

After 1818, land cession treaties between the Crown and Native peoples regularly included provisions for reserves of land as a home for each community and as a place to earn a living (Nin Da Waab Jig 1987:29). Other Aboriginal groups (Bands) obtained their reserves before 1818 in different ways. Walpole Island became a reserve by being omitted from the 1790 land cession (Nin Da Waab Jig 1987:29). Despite these treaties, reserve lands were often settled by non-Native populations. Beginning in the early 1800s, encroaching white settlers took illegal possession of vast tracts of land on the island, forcing the local population to less fertile, peripheral reserve lands. The Government was ambivalent about removing the squatters because they fulfilled the ultimate goals of “progress” and “development” by cultivating the land (Nin Da Waab Jig 1987:32). In his report, J.W. Keating (Assistant Superintendent -
Western Superintendency and Walpole Island, 1838-1845) writes, “The Indians are now tripled in number…. as to the effect of such an influx of whites, it can be summed up in one word: ‘Ruination’ of the Indians” (Canada 1843).

The eventual expulsion of white squatters coincided with an influx of Potawatomi, Chippewa, and Odawa groups who migrated to Upper Canada as a result of the Indian Removal Act of 1830 (an American policy of removal of Native peoples from the regions south of the Great Lakes to large reservations west of the Mississippi). Potawatomi, Chippewa and Ottawa groups who did not want to move west migrated into Upper Canada (Clifton 1973; 1975, Nin da Waab Jig 1987:35). Although the Potawatomi did not create competition for farmland, they did put a “new and excessive pressure” on game in the surrounding area (Nin da Waab Jig 1987:36). The group’s ‘predilection for the hunt’ and reluctance to become farmers was viewed negatively by the Government, who strongly discouraged traditional subsistence strategies and considered the group a threat to the ‘progress’ of Walpole Island residents who had begun to adopt agriculture as their primary subsistence strategy. Population pressure and refusal to abandon their hunting lifestyle were the reasons behind a plan to re-locate the Potawatomi to Manitoulin Island (Nin Da Waab Jig 1987:36-37). Although a large number of Potawatomi settled permanently on Walpole Island, they suffered a great deal during the early years of their settlement. Those experiencing famine and deprivation were refused help from the Government; only those who were willing to move to Manitoulin Island were considered for financial aid (Nin Da Waab Jig 1987:36).

Recognition as a single political entity and the unequal distribution of annuities

The Chippewa of Sarnia, Kettle Point and Walpole Island were initially treated as a single entity by the Canadian Government. However, an argument over the distribution of annuity goods (land payments) in 1835 led the Walpole Island First Nation to file a request with the Government for separation from the other reserves. The request was denied, but Walpole Island’s distinct status was recognized by the Government with the appointment of a separate Indian Agent to the community (J. W. Keating) (Nin Da Waab Jig 1987: 42). Despite being recognized as a separate political entity, the separation of reserve lands and trust fund accounts, and proper division of annuities did not follow. In 1838 when cash was used for annuities for the first time, the distribution of these payments was divided unevenly, with eight elevenths going to the Sarnia reserve and three elevenths going to Walpole Island (Nin Da Waab Jig 1987:42). Although a new proportion of annuities was decided in an 1848 agreement, the amount received by the Walpole Island First Nation increased only slightly and remained the same even after the population increased when half of the annuitants resident at Riviere Aux Sable moved to the island in 1850 (Nin Da Waab Jig 1987:43). Residents depended on annuity payments during times of hardship (e.g., crop failures, harsh winters). The sporadic distribution of annuities and gifts presented another form of economic stress. In one of his reports, local Indian Agent J.W. Keating describes the “misery” of residents “suffering from hunger and cold” as a result of a “lamentable delay in receiving the goods [annuities]” (POA, Keating Letterbook: letter to Higginson, March 1851).

Transition to a sedentary lifestyle and agricultural economy

It wasn’t until the settlement of Sombra, Ontario in the 1820s pushed the Walpole Island Band off the mainland that they settled permanently on the islands (Nin Da Waab Jig 1987:41). Transition from hunting and gathering to an agricultural economy brought drastic changes to traditional settlement patterns, systems of landholding, and diet. The aggregation of Native groups on reserves resulted in population growth and greater demands for resources.
Crowded living quarters provided an ideal environment for the transmission of airborne diseases like tuberculosis (Cassel 1971), while the close proximity of domesticated livestock to human dwellings facilitated the spread of zoonotic diseases (Swedlund and Armelagos 1990, Barta this volume). Although agriculture was encouraged, Aboriginal farmers were provided with “the barest of farming implements and technical knowledge” (Nin Da Waab Jig 1987:30). Communities lacked the fundamental infrastructure to support their growing populations and agricultural economies. Outbreaks of hog cholera and typhoid fever on the island in the late 1890s were caused by water contaminated by animal faeces and human sewage. In a report discussing outbreaks of waterborne diseases in the community, Alexander McKelvey states that, “as a whole, these people are not healthy, and will never be healthy until more attention is paid to the quality of water they use” (Canada 1896).

Although Walpole Island residents were proficient agriculturalists, they were still vulnerable to the catastrophic effects of poor weather and meager harvests. Ebenezer Watson (Visiting Superintendent - Western Superintendency, 1878-1883) reports on how the crops of 1881 “were in many cases greatly deficient”, and “the aged, infirm, and sick” were sustained through supplies provided by the Councils of the different Bands (Canada 1881). In many cases, Indian Agents unjustifiably attributed crop failures and the deprivation that followed to the “ineptitude” of Native farmers. Watson blames poor crop yields on the farmers themselves, who he believes failed to “put enough effort toward clearing the land”, and lacked “the foresight to prepare for times of want” (Canada 1881:71). Negative health implications associated with a diet based primarily on agricultural staples include episodic starvation, malnutrition (e.g., protein vitamin-deficiency) and increased susceptibility to infectious disease (Moffat and Herring 1999; Reddy et al. 1976, Lunn 1991).

Insufficient health care services

Jamieson’s reports and personal correspondence make frequent reference to the many difficulties he encountered trying to secure medical aid for Walpole Island residents. In his discussion of the major smallpox epidemic of 1859, he writes:

> The medical man in the neighbourhood declined to assist me, alleging that if he did so he would displease his [white] patrons. The white man kept aloof once the Island had become stricken with the plague (VPCMA Jamieson file: Report to the Lord Bishop of Huron, 17 July 1862).

Jamieson’s correspondence with the Department of Indian Affairs reveals confusion and miscommunication regarding issues of health care delivery. In 1879, the Anglican Minister submitted an application for medical aid to the Department of Indian Affairs. The application was denied. In his follow-up letter to L. Vankoughnet (Deputy Superintendent General, Indian Affairs), Jamieson takes issue with the Department’s opinion that “there was not enough sickness among the Indians [at Walpole Island] to justify the expense of a Dr.’s services among them” (VPCMA, Jamieson file: Letter to L. Vankoughnet, 29 December 1879). Jamieson proceeds to detail the poor health status of community members, citing 17 deaths in the preceding six months, a number he refers to as disproportionately high for a “population of 600 Chippewas” (VPCMA, Jamieson file: Letter to L. Vankoughnet, 29 December 1879). In his response, Vankoughnet attempts to clarify the Department’s position, which he explains was not a refusal to cover medical services but a rejection of the proposal to station a physician in the Walpole Island community. He reiterates the Department’s policy on the payment of the medical bills of Aboriginal patients, a policy he assumes Jamieson is (or ought to be) well-acquainted with, and suggests implementing a system in the community that has been employed
on nearby reserves¹⁰ (VPCMA, Jamieson file: Letter to Andrew Jamieson from L. Vankoughnet, 12 March 1879). Despite the Deputy Superintendent General’s affirmation of the existence of suitable health care provisions for reserve populations, the perennial scarcity of adequate health services was (and continues to be) a serious problem for Native communities in Canada and was a constant source of discontent for Jamieson, as evidenced by his lamenting comments on the subject. Furthermore, discrepancies between Jamieson’s reports on Aboriginal health issues and those of his Indian Agent contemporaries illuminate differences in how missionaries and Indian Agents both perceived and reported community health crises, and underscore the divergent and contesting priorities of church and state in regards to the future welfare of Native peoples in Canada at that time.

Conclusion

There are very few locations where the full, detailed sequences of changes in mortality from the 19th to the 20th century have been observed in a single Aboriginal community (Hoppa 1998:177). The wealth of information contained in the Walpole Island Anglican parish records offer valuable insights into disease ecology, mortality trends and the nexus of social and economic factors that shape community health profiles. As in other First Nations communities, the implementation of assimilation policies led to drastic changes in land use, resource access, subsistence economies and settlement patterns. These transformations greatly reduced community members’ self-sufficiency and precipitated periods of socioeconomic deprivation, which in turn, both elevated the local population’s risk of contracting infectious diseases and compounded the severity of disease outbreaks.

Syndemics and political ecology models illuminate the limitations of reductionist epidemiological paradigms that emphasize exposure-disease associations as self-contained, homogeneous or independent phenomena. As studies in the field of medical anthropology have shown, the poor health outcomes of marginalized and disenfranchised populations are, in essence, biological manifestations of inequality (Farmer 1999; 2003). In this regard, both ‘historicising’ and ‘politicising’ health is crucial to bringing into high relief the ‘ultimate causes’ of disease—those transpiring from global-local processes, bureaucratic policies and institutional practices rooted in systems of inequality, discrimination and exploitation. Adopting a theoretical model that frames health as the product of historical contingencies, differential power relations, and impinging political and economic forces is both constructive and necessary for the development and implementation of ethical and efficacious strategies for responding to present-day Aboriginal health issues and future public health crises.

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Notes

1 These groups share a similar culture and cognate languages and are connected through a political alliance known as the Three Fires Confederacy.

2 A religious society that funded much of Jamieson’s missionary work.

3 This protocol combines the content-oriented goal of deconstructing historical ‘descriptions’ of past events, and the source-oriented goal of understanding the ways in which the author’s mindset, cultural background and social and political status shape the content of analysis.

4 Medical diagnoses are influenced by a number of factors, including the prevailing philosophies, taxonomies and perceptions of disease of a particular time period, the physician’s diagnostic ability, approach to disease causation, understanding of pathological processes, and the length of time that has been spent caring for the person prior to death (Sartwell and Last 1980:20).

5 Determining the sex distribution of deaths is complicated by the fact that burial records list the Ojibwe names of the deceased, which makes the identification of gender difficult. The recording of infant deaths in gender-neutral terms further hinders this type of investigation.
The application of a syndemics model to public health issues has led to seminal studies on the relationship between HIV and TB (Ho 1996, Rose et al. 2002), Influenza A and Respiratory Syncytial Virus (RSV) (Zhao et al. 2002), Hepatitis C and alcoholism (Prakesh et al. 2002), and socioeconomic status (SES) and asthma (American Lung Association 2003).

A term often used to designate Ojibwe and Odawa (Ottawa) Nations.

Research on the political ecology of human biology has focused on environmental risk in urban settings (Schell 1997), the social and biological effects of tourism and the biology of poverty (Daltabuit and Leatherman 1998), the biology of conflict (Kalipeni and Oppong 1998), and health and disease in prehistoric and historic populations (Armelagos and Barnes 1995, Goodman et al. 1998).

The reserve system was initially intended to protect land from takeover by sale to settlers or gradual loss to squatters, however, the Government essentially viewed reserves as “a transitional stage towards individual land holding [based] on the settler model” (Nin Da Waab Jig 1987:30).

At nearby Sarnia and Kettle Point reserves, medical bills were covered by the Government so long as they had been “passed by Band Council and certified by medical men rendering them - to be composed of charges at the lowest rates charged to the poorest class of white people”. These would later to be passed along to the Superintendent for payment (VPCMA Jamieson file: letter to Andrew Jamieson from L. Vankoughnet, 12 March 1879).
Chapter 12
Norway House Residential School and Tuberculosis, 1900-1946
Melissa Stoops

The Norway House Residential School (NHRS) was part of Canada’s Native Residential School System. The main purpose of the Residential School system, which operated from 1879 until the late 1970s, was to culturally assimilate Aboriginal people into ‘white’ society and to eliminate the federal government’s legal responsibility to Aboriginal people (Miller 1996). The residential schools, which were jointly operated by the churches and the Department of Indian Affairs (DIA), were preferred by the government over day schools because they removed the children from the influences of their own homes (Miller 1996). The various church denominations owned and operated the schools while the DIA provided funding, established regulations, and conducted inspections of the schools (Miller 1996).

There were many problems with the Residential School system as a whole, one of them being the overall health of the children. The children suffered high rates of morbidity and mortality, particularly from tuberculosis. The most robust reports regarding the morbidity and mortality rates within the schools are those of Dr Peter Bryce, Chief Medical Officer of the DIA, contained in his health reports from 1907 and 1909 (Bryce 1907, 1909). His 1907 report, in which he reported on inspections of 35 schools in Manitoba, Saskatchewan, and Alberta, found that an average of twenty-five percent of all former students from the schools were known to be dead, with TB as the main cause (Bryce 1907). Dr Bryce’s 1909 report, for which he conducted a medical examination of 243 residential school children, found similar results. In the report, he estimated that the annual death rate of students in residential schools was roughly 80 per 1,000, with TB as the main cause of death (Bryce 1909). The health problems of the school children have been linked to the numerous deficiencies of the residential schools such as overcrowding, poor ventilation, poor nutrition, the heavy work load of the students, little to no medical facilities, and chronic under funding (Bryce 1907, Kelm 1998, Lux 2001, Miller 1996, Milloy 1999).

Additionally, high morbidity and mortality rates of tuberculosis and the associated living conditions were a widespread problem in the home communities of the children. By the end of the 19th century, tuberculosis had become the major health problem among Aboriginal populations and continued to be so well into the 20th century. Mortality rates among Aboriginal populations from tuberculosis were ten to twenty times greater than those of the general population (Waldram et al., 1995: 61). The high prevalence of tuberculosis has been linked to the relocation of Aboriginal populations to reserves, poor living conditions, and loss of traditional subsistence methods. Many of the children were likely exposed to the disease at home prior to enrolment; however, children were also exposed while at school which further contributed to the spread of the disease. It was not uncommon for children who arrived at the residential schools in good health later to test positive for TB and carry the disease home (RCAP 1996b).

It is impossible to separate the poor health of the children within the residential schools from the health conditions on the reserves. The residential schools played a role in the larger tuberculosis epidemic among Aboriginal populations. There have been very few studies of tuberculosis or other health issues within a specific residential school (e.g., Keller 2002). Most studies of the health of residential school children have looked at the residential school system as a whole (e.g., Bryce 1922, Miller 1996) or schools within a geographical region.
(e.g., Kelm 1998, Lux 2001). This article examines the impact that tuberculosis had within one specific residential school, the Norway House Residential School. The NHRS was not included in either of Dr Bryce’s reports but was found to be similar to the other residential schools.

Materials and Methods

Several different sources of archival material were consulted and used to reconstruct the school children’s health and the conditions at NHRS. The bulk of the material came from official documents of the DIA and church officials in the RG 10 School Files and the *DIA Annual Reports*; memoirs from Reverends J.A. Lousley (1948) and R. Chapin (1972), both former principals; Hudson’s Bay Company post journals (HBCA, Cross Lake Post Journal 1900-1940, God’s Lake Post Journal 1900-1940, Island Lake Post Journal 1900-1940, Norway House Post Journal 1900-1939, Oxford House Post Journal 1901-1937); and, to a lesser extent, the parish records, specifically the burial records for the communities whose children attended NHRS (ACCA, God’s Lake Burial Records 1900-1940, Norway House Burial Records 1902-1937, UCCA, Oxford House Burial Records 1918-1951).

The main method used in this study involved locating, reading through the available archival materials, collecting and interpreting the relevant information. While studying the various materials available, prominent themes were identified. The relevant information from letters and reports was then collected and organized by related topics. Given that the main focus of this study is on the health of the children, any commentary regarding the issue was noted. Special attention was also paid to observations regarding diet, overcrowding in the school, and general complaints and concerns about the condition of the school building in order to get a sense of the quality of the environment in which the children lived. It was important to know whether NHRS fit the picture of other residential schools and disease patterns described by other researchers (Keller 2002, Kelm 1998, Lux 2001, Miller 1996, RCAP 1996a).

The vast majority of the information used in this study came from the *DIA Annual Reports* and the RG 10 School Files; however, there are several limitations with these sources. The NHRS Principal’s Annual Report published in the *DIA Annual Reports* from 1901 to 1913 only gave a summary of the general health of the children for the year and indicated whether or not there were any major illnesses or deaths. Complete details on these cases were often lacking (DIA, Hardiman 1901, 1902, Lousley 1903 – 1913). However, this is to be expected since the annual report was intended to give the DIA an overview of the entire school year, and focused on all aspects of the school. After 1913, information on health and illness is sketchy and scattered among various other records. For some years there is no information available. Due to the limitations of the sources, the majority of the analysis is necessarily descriptive in nature. For example, tuberculosis, often referred to as consumption and scrofula in the records, is continually mentioned as problematic in the school but at no time is the total number of children affected given. As a result, the prevalence rate of TB in NHRS cannot be determined for this study.

Background on Norway House Residential School

The NHRS, located in Norway House, Manitoba, was owned and operated by the Methodist Church (Figure 1). The Methodist Church opened the Brandon Institute in 1895, a large residential school located in southern Manitoba. However, many Aboriginal families living in Norway House and in communities further north who wished to send their children to school
thought that Brandon was too far away (Stephenson 1925). In response to this concern, three years later, the Methodist Church sent a request to the Department of Indian Affairs to provide funding for the construction of a boarding school near the Norway House Reserve. Norway House was considered an ideal location for a school because it was “a centre from which quite a number of bands [could] be reached” (NAC, Sutherland to DIA, June 22 1898). The DIA agreed to provide $3,000 toward the construction of the school and a yearly per capita grant of $72 for 50 pupils (NAC, McLean to Sutherland, April 19 1898).

Construction of the school building was delayed for almost a year due to disagreements between the Methodist Church and the DIA on the construction costs and total amount the DIA agreed to provide toward the building cost (NAC, Branson to McKenna, April 25 1899, Sutherland to Smart, April 1 1899, Smart to Sutherland, April 12 1899, Sutherland to Smart, April 15 1899, Branson to McKenna, April 25 1899). Construction finally began in 1899 and was completed by 1900. NHRS, the first residential school located on Lake Winnipeg, opened in the fall of 1900 with 58 students enrolled (DIA, Hardiman 1901). In February 1913, the original school building was destroyed in a fire. However, following the fire, the school remained open and used the vacant Norway House hospital building and the old Hudson Bay Company store as temporary accommodations (NAC, Lousley to Ferrier, Feb 26 1913, Feb 27 1913, DIA, Lousley 1913). A new school building, much larger than the original, was completed in October of 1914 (DIA, Jones 1916). The second school building was also destroyed in a fire on May 29, 1946 (NAC, Goodman to Hoey, May 29 1946).

The residential school was not replaced until 1952 (Apetagon 1991). However, by this time there had been major changes within the school as well as the Native Residential School System as a whole. Due to growing opposition to the residential schools by Aboriginal communities, changes in the school curriculum shifted the emphasis to the children’s education rather than vocational training. As well, there was stricter enforcement of the health regulations and better provision of medical care in the schools (Miller 1996, Shkilnky 1985). The health regulations were still not entirely comprehensive nor effective but they were an improvement. Old school buildings were remodelled, new buildings were constructed according to health requirements, the diet was generally improved, children received regular medical attention, and children with active TB cases were placed in sanatoria (Miller 1996). Additionally, there was a gradual shift away from the Residential School system to federally-run day schools on the reserves (Miller 1996, Shkilnky 1985). Due to these factors, as well as the lack of records, conditions after 1952 are not included in this study.

**Demographic Profile of the Children**

The majority of children who attended the NHRS were from the communities within the Norway House Agency: Norway House, Cross Lake, Oxford House, God’s Lake and Island Lake (Figure 1). Most of the children were from Norway House and Cross Lake; the number of children from the other communities was typically smaller (Apetagon 1991, NAC, Blackford to Scott, Jan 9 1928). Occasionally children from Berens River, Nelson House and Trout Lake, Ontario attended the school but it is difficult to determine the exact number from the records (DIA, Lousley 1911). Enrolment for the first 13 years averaged 57 students. After the larger school building was built in 1914, enrolment averaged 96 students, despite the fact that the capacity of the two school buildings was 50 and 80, respectively. Adequate information to determine the average age of the children attending the school during the period covered in this study is not available. Information on the ages of the children at the time of admission and at discharge can be derived from the school records for 1934 to 1941.
The age at admission for 124 children and age at discharge for 120 children is available. The average age of admission during this period was about 9 years of age and average age of discharge was 16 years old. Generally, there was a higher percentage of girls enrolled in the school than boys (DIA 1914-1936, DMR 1937-1939, NAC, Admissions and Discharges 1933-1941, Blackford to Scott, Jan 9 1928).

Figure 1  Map of the home communities of children attending Norway House Residential School. Map adapted from National Atlas of Canada (http://atlas.gc.ca).
Tuberculosis was the most commonly reported disease at the NHRS, as well as in other residential schools (Bryce 1907, 1909, Kelm 1998:66, Miller 1999: 304, Waldram et al. 1995: 136). However, it is not possible to estimate the prevalence rate of tuberculosis among the children due to the lack of complete and accurate data. Reports on the health of children were generally infrequent and would only mention the presence of TB, although, they often state that it was the main cause of illness and serious cases that required extensive medical care or resulted in death (see Table 1). Tuberculosis was first mentioned at NHRS in the 1904 report, although it was likely present in the school prior to this (DIA, Lousley, 1904). It continued to appear in the Principal’s Annual Reports until 1913 when they were no longer included in the published DIA Annual Reports. Following 1913, reports on the health of the children were very infrequent but the available reports typically mentioned tuberculosis.

<table>
<thead>
<tr>
<th>School Year</th>
<th>Years in which tuberculosis is mentioned in the Norway House Residential School records. The terms consumption and scrofula are historic terms for tuberculosis of the lungs and tuberculosis affecting the lymph nodes of the neck.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1903-04</td>
<td>Several children sent home on sick leave due to TB; 5 deaths due to TB</td>
</tr>
<tr>
<td>1906-07</td>
<td>Scrofula and consumption reported as problematic; 9 deaths due to TB</td>
</tr>
<tr>
<td>1908-09</td>
<td>Three deaths due to TB</td>
</tr>
<tr>
<td>1909-10</td>
<td>Scrofula and consumption reported as problematic</td>
</tr>
<tr>
<td>1910-11</td>
<td>Four serious cases of consumption resulting in one death</td>
</tr>
<tr>
<td>1911-12</td>
<td>Consumption and scrofula chief cause of illness</td>
</tr>
<tr>
<td>1912-13</td>
<td>Three seriously ill children: one consumption; one &quot;bad hemorrhages from the lungs&quot;</td>
</tr>
<tr>
<td>1914-15</td>
<td>Several children treated at hospital due to poor diet and &quot;physical pre-disposition to tubercular troubles&quot;</td>
</tr>
<tr>
<td>1922-23</td>
<td>One child under care doctor due to active case of TB of lungs</td>
</tr>
<tr>
<td>1923-24</td>
<td>Health good except for &quot;a few cases of glands&quot;</td>
</tr>
<tr>
<td>1930-31</td>
<td>DIA concerned about the health of the pupils; tuberculosis prevalent; one child under doctor’s care</td>
</tr>
<tr>
<td>1932-33</td>
<td>One child discharged due to TB</td>
</tr>
<tr>
<td>1933-34</td>
<td>One child discharged due to TB</td>
</tr>
<tr>
<td>1934-35</td>
<td>Two children discharged due to TB</td>
</tr>
<tr>
<td>1935-36</td>
<td>One child with inactive TB of lungs admitted; 3 children not admitted due to active cases</td>
</tr>
<tr>
<td>1936-37</td>
<td>One child admitted with &quot;infected gland&quot;</td>
</tr>
<tr>
<td>1937-38</td>
<td>One child admitted with TB of lungs and glands; one child discharged due to TB</td>
</tr>
<tr>
<td>1938-39</td>
<td>Three children admitted with inactive TB</td>
</tr>
<tr>
<td>1939-40</td>
<td>One child admitted with infected glands</td>
</tr>
<tr>
<td>1940-41</td>
<td>One child discharged due to TB; one died of TB following typhoid fever infection</td>
</tr>
</tbody>
</table>
Tuberculosis was also the most common cause of death among the children. Of the 36 known deaths at the school, nineteen (53%) were attributed to TB (see Table 2 and Figure 2). The majority of the known deaths occurred prior to 1911. There is roughly a 20 year gap (1913-1933) in the records regarding deaths at the school so it is possible that more occurred than were reported. Additionally, deaths were not always reported and if a child died after being sent home on sick leave, it was not reported as a death in the school.

Table 2: Known deaths and causes at Norway House Residential School.

<table>
<thead>
<tr>
<th>Year</th>
<th>Deaths</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>1900-01</td>
<td>1</td>
<td>Unknown</td>
</tr>
<tr>
<td>1902-03</td>
<td>5</td>
<td>4 whooping cough; 1 eating poisonous berries</td>
</tr>
<tr>
<td>1903-04</td>
<td>5</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>1904-05</td>
<td>3</td>
<td>Scarlet fever; measles</td>
</tr>
<tr>
<td>1906-07</td>
<td>10</td>
<td>9 tuberculosis; 1 spinal meningitis</td>
</tr>
<tr>
<td>1908-09</td>
<td>3</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>1910-11</td>
<td>1</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>1918-19</td>
<td>2</td>
<td>Influenza</td>
</tr>
<tr>
<td>1933-34</td>
<td>1</td>
<td>Unknown</td>
</tr>
<tr>
<td>1940-41</td>
<td>5</td>
<td>3 typhoid fever; 1 TB following typhoid fever infection; 1 unknown</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2 Percentage of known deaths due to tuberculosis, other infectious diseases and unknown/other. Tuberculosis accounted for half of the known deaths at Norway House Residential School.
The greatest number of deaths, almost a third of the total number, occurred during a single school year (1906-07). Ten deaths occurred in total with nine due to tuberculosis. The poor health of children during the year was specifically attributed to the overcrowding and poor conditions at the school. Sixty-five students were enrolled at the beginning of the year; fifty was the capacity of the school. The high enrolment for the year, according to school officials was “probably more than should have been in the dormitories considering the lack of ventilation” (NAC, Report of NHBS, 1907). The school was also reported as being “poor and cold” and “scarcely fit for use” (DIA, Semmens 1907: 317). Recommendations were made to close the school for a year due to the poor health of the children and the poor conditions of building; however, these recommendations were not acted on for financial reasons (NAC, Semmens to Laird, Sept 7 1907). The school would not have received funding from the DIA had it closed for a year. There were no deaths during the following year but, according to the principal, there was still “quite a lot of sickness” (DIA, Lousley, 1908).

Conditions at Norway House Residential School

Many of the conditions at NHRS, as well as the other residential schools, are ones that are commonly associated with tuberculosis. The schools were often under funded, overcrowded, had inadequate ventilation and the children fed a poor diet. Additionally, children were often admitted regardless of any existing TB infections despite regulations barring their admission. These conditions have been linked to the high rates of morbidity and mortality among the children in the schools (Bryce 1907, Kelm 1998, Lux 2001, Miller 1996, Milloy 1999). The Norway House Residential School was no exception.

The method of funding the school system has been cited as the main reason for many of the poor conditions at the schools (Miller 1996). The schools were chronically under funded by both the Federal Government and the churches. In the early years of the Residential School system, the government covered all the costs but it became difficult to control the spending of the school principals and, as more schools were opened, the system became too expensive to sustain. In 1892, the DIA began to provide only the initial building cost and then paid for major repairs and yearly funding in the form of Per Capita Grants (PCG) based on attendance levels.

The schools were expected to use the money for daily operations which included feeding and clothing the children, supplies, salary for the staff, and minor repairs. However, the amount of funding was inadequate and had major implications for the conditions found in the schools (NAC, Benson to Pedley, Aug 21 1905; RCAP 1996a). A funding system based on attendance figures forced school principals to maintain the maximum attendance so that the full grant amount could be obtained. This strategy often contributed to overcrowding in the schools and to a reduction in attention to the health status of potential pupils. Overcrowding also increased the risk of infectious diseases spreading easily within the schools. In addition, principals had less funding for major expenditures, such as food, and had to increase the school’s revenue with products harvested on the schools’ farms. The children were often used to provide farm labour which was designated as vocational training (Miller 1996).

At the NHRS, the original school building’s capacity and the PCG limit was 50 pupils but enrollment generally exceeded the capacity (Figure 3). Between 1900 and 1913, the enrollment averaged at 57 students and ranged from 46 to 65. The new school constructed after the 1913 fire was designed to house 80 students and this was set as the PCG. Any more than 80 students was considered “too many children … from a health point of view” (NAC,
McLean to Ferrier, June 5 1915). However, within a year of the new building’s completion, 87 children were in attendance at the school.

In 1922, the DIA raised the per capita grant from 80 to 105 students even though they were aware that this was more children than should have been in the school (NAC, Ferrier to McLean, Oct 4 1922, McLean to Ferrier, Oct 10 1922). The local Indian Agents and doctor protested this increase and made numerous requests to decrease the enrolment levels for health reasons (NAC, Gordon to MacKenzie, Oct 7 1925, Turpel to DIA, May 20 1930). In response to additional requests for increases from school officials, the DIA stated that, “…the present pupilage of 105 must not under any circumstances be exceeded, until funds can be found for an addition. Serious danger to the health of the pupils would be the result of overcrowding the dormitories” (NAC, McLean to Blackford, Jan 20 1926).

Only one school principal, Rev. Shoup, decreased the enrollment (1930 -1934) because he recognized that the school was very overcrowded. There was a slight improvement in the overall health of the children, and the doctor reported that the children were better fed and clothed during this short period (NAC, Shoup to MacKenzie, Jan 5 1932). However, enrolments went back up after he left.

In addition to overcrowding due to the funding system, children were often admitted despite their health status. Admission regulations required the refusal of admission of any child who was considered tubercular, but this was rarely, if ever, enforced. As Miller puts it, “the regulations often were more honoured in the breach than in observance” (Miller 1996: 301). Dr E. L. Stone, who was the attending physician in Norway House in the 1920s and was
responsible for conducting the medical examination of children prior to admission, had the following to say regarding admission requirements and tuberculosis:

I cannot recall any child, from any Reserve except Island Lake, whom I should not have rejected for tuberculosis if the regulation had been strictly adhered to. Those who appear to have active tuberculosis are rejected. Those whose infection appears dormant are passed. They have to be. Otherwise there would be no pupils in the schools. There are no better to be had. They do quite as well in schools as they would do outside, but, at that, there are too many deaths of pupils during their education (Stone 1925: 247-248).

Of the 130 children admitted between 1933 and 1941, eight percent (11) of the applicants had some form of TB. Three of the children with TB were not approved for admission due to their condition: two had active cases of TB of the lungs, and the other had an inactive case of TB of the lungs. Tuberculosis had been a problem in Norway House and the surrounding communities for some time and was reported as a common infection in Norway House by 1887 (Maundrell 1941). It continued to be a problem in northern communities well into the 20th century. When Dr Stone submitted a health report for the Norway House Agency in 1925, he reported that the chief cause of illness was tuberculosis (Stone 1925). The majority of the children who were enrolled in NHRS would have likely been exposed to the disease at home due to its high prevalence rate. Had the regulation barring children with TB from admission been properly observed, the school would have been empty (Stone 1925). This breach in policy was a common occurrence among the residential schools in order to keep them full (Bryce 1907, 1909, 1922, Miller 1996).

Despite the presence in the school of children already infected with TB, officials believed that the school environment was still “healthier” than the homes of the children and, in some cases, would be a better place for a child to live. There is some evidence for this from the admission records of two children. In 1937, a child with a TB infection in both the lungs and glands applied for admission. Along with his admission and medical forms, the school principal, Rev. Chapin, included a letter stating that:

Any TB he has had has been arrested and he is in apparently good health at the present time. This being so he is no menace to the other children. The home he comes from is terribly poor and he ought to stand a much better chance in the school of getting built up against further reinfection (NAC, Chapin to Lazenby, Dec 24 1937).

Another example comes from 1940, when a girl, aged 16, applied for admission. She was not infected with tuberculosis; however, it was prevalent in her family. Again, Rev. Chapin included a letter along with her admission forms in order to justify her admission to the school. An excerpt of the letter follows:

The parents now have two younger children in the school. The home is not a healthy home. They lost one child from tuberculosis this winter. The father is now himself in poor condition. And so the parents are anxious to get this girl in the school for a couple of years, both to get a bit of training and be cared for physically. The Doctor too is anxious to get her out of her home where she is so liable to infection. Before letting her into the school however he x-rayed her chest to make sure there was no disease (NAC, Chapin to Lazenby, May 2 1940).

Her admission to the school was denied due to her age. Regulations required that the children be discharged at the age of 16 (NAC, Philip to Lazenby, May 21 1940).

However, the school environment was not always healthy for children with or without tuberculosis. For instance, the diet in most Native Residential Schools was considered sub-
par and contributed to the children’s susceptibility to disease, particularly tuberculosis (Miller 1996). The food was usually of poor quality, inadequate quantity, and lacked the variety needed to provide all the necessary nutrients. It was not uncommon for doctors to send reports to the DIA on the relationship that they observed between the poor diet in the schools and tuberculosis among the school children (RCAP 1996a).

At the NHRS, numerous complaints about the food led to an investigation of the diet by two DIA officials in 1915. The local Indian Agent was the first to investigate at the beginning of the year. He claimed that the food was “good and substantial” and that there were no grounds for the complaints. He essentially claimed that the children were complaining for the sake of it (NAC, Report on complaints, Jan 6 1915). However, due to continuing complaints, John Bunn, the Inspector of Indian Agencies, conducted a second investigation later in the year. His results differed greatly from the Indian Agent’s report. As part of his report, the school principal had to submit a copy of the school menu (Table 3).

Table 3  Menu of the NHRS for 1915 (Source: NAC, RG 10 Vol 6268, file 581-1, part 1).

<table>
<thead>
<tr>
<th>Day</th>
<th>Morning Breakfast</th>
<th>Noon Dinner</th>
<th>Night Supper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sunday</td>
<td>Granules Porridge, Bread &amp; Tea</td>
<td>Pork &amp; Beans, Pie, Bread &amp; Water</td>
<td>Bread &amp; Jam, Tea</td>
</tr>
<tr>
<td>Monday</td>
<td>Baked Beans, Bread &amp; Tea</td>
<td>Fish or Meat, Bread &amp; Water</td>
<td>Fish, Bread &amp; Tea</td>
</tr>
<tr>
<td>Tuesday</td>
<td>Oatmeal Porridge, Bread &amp; Tea</td>
<td>Fish or Meat &amp; Rice, Bread &amp; Water</td>
<td>Prunes, Bread &amp; Tea</td>
</tr>
<tr>
<td>Wednesday</td>
<td>Granules Porridge, Bread &amp; Tea</td>
<td>Fish or Meat, Split Peas, Bread &amp; Water</td>
<td>Fish, Bread &amp; Tea</td>
</tr>
<tr>
<td>Thursday</td>
<td>Oatmeal Porridge, Bread &amp; Tea</td>
<td>Fish or Meat, Pot Barley Bread &amp; Water</td>
<td>Apples, Bread &amp; Tea</td>
</tr>
<tr>
<td>Friday</td>
<td>Oatmeal Porridge, Bread &amp; Tea</td>
<td>Fish or Meat, Bread &amp; Water</td>
<td>Fish, Bread &amp; Tea</td>
</tr>
<tr>
<td>Saturday</td>
<td>Oatmeal Porridge, Bread &amp; Tea</td>
<td>Fish, Bread &amp; Water</td>
<td>Bread, Butter &amp; Tea</td>
</tr>
</tbody>
</table>

The Fish or Meat is to be boiled with some of the dried vegetables mentioned above. Pies are made once a week, 1 1/2 lb Lard to a making, pie cuts in 6 pieces. For a change the Fish or Meat may be fried or roasted. Yellow sugar to be used in tea, night and morning, also in stewing apples or making pies. Yellow sugar, with syrup every alternate morning, served on Porridge. When fish or meat is not in stock, dried vegetables, as the Principal may direct, may be used.

Fish: These are White [Fish], Pickerel, Pike, Gold Eyes, Sturgeon, Red and Grey Suckers
Meat: This if Beef, Moose Meat, Venison
Vegetables: Beans, Split Peas (dried)
Cereals: Rolled Oats, Granules, Pot Barley, Rice

According to Bunn’s findings, the quality of bread was “open to criticism,” the quality of fish was not always the best and sometimes poorly cooked, there was an absence of fatty food, and there was a limited quantity of vegetables. The only available vegetables were turnips, beets, cabbage, and carrots. Potatoes were available at the beginning of the year but were only used for four meals (NAC, Bunn to Scott, Sept 24 1915). In addition, the local doctor, Dr. Norquay,
informed Bunn that he had treated several children from the school. Their conditions were described as a “low physical condition” that generally improved and disappeared after receiving “proper nourishing food” at the hospital. The doctor noted that the primary cause for these illnesses was the “lack of proper nourishing food, implemented also by a physical predisposition to tubercular troubles” (NAC, Bunn to Scott, Sept 24 1915).

Following the investigation, Bunn suggested that the doctor supervise the diet of the school and inspect it on a regular basis. (NAC, Bunn to Scott, Sept 24 1915) The Department approved the medical supervision of the diet at the school and instructed the local Indian Agent to deal with the matter in monthly reports (NAC, Scott to Bunn, Sept 30 1915). By 1922, a school nurse looked after the food and was in charge of the kitchen (NAC, Graham to McLean, Feb 23 1922). After 1922, the records contain no information regarding the diet of the children. However, other studies have found that the diet in residential schools continued to be sub-par (Miller 1996, RCAP 1996).

Conclusions

It is impossible to determine the prevalence of tuberculosis at NHRS due to the nature of the information available in the archives. However, what is known is that tuberculosis was present in the school and was a common cause of illness and death among the children. If the regulation barring admission of children known to be infected with TB had been adhered to, it would have at least kept children with active cases of TB out of the schools. However, this regulation was not consistently followed and children infected with TB were present in the schools. This, combined with the conditions of the school, such overcrowding and poor diet, increased the children’s susceptibility to illness and increased the chance of latent cases of TB becoming active, thus contributing to the spread of the disease.

Acknowledgements

I would like to acknowledge the Department of Anthropology, McMaster University, Canada and Dr Ann Herring, who served as my supervisor. This article is based on findings from my M.A. thesis entitled “Health Conditions at Norway House Residential School, 1900-1946.”

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Chapter 13
A Political Ecological Perspective on Housing Conditions and Tuberculosis Transmission among Māori in Two Different Geographical Areas during the Early- and Mid-20th Century
Catherine Finn

Rates of tuberculosis among Māori are currently, and have historically been, eight to ten times those of Pākehā (Lange 1999:30, Turnbull 2002:8). In 1936, the age-sex standardised rate of tuberculosis mortality for Māori was 50.4 per 10,000 people, as compared with the Pākehā rate of 5.3 (Finn 2007:45). Tuberculosis mortality was responsible for between 17.2 and 25.9% of total Māori deaths between 1918 and 1945. This is in comparison to the Pākehā situation, in which tuberculosis deaths made up between 3.7 and 7.4% of total Pākehā deaths during this time period (Finn 2007:46).

The links between tuberculosis, marginalisation and substandard housing are well established (see Farmer 1997a:347, Leon 2001:69-70, Acevedo-Garcia 2000, and Drucker et al. 1994). Because Māori have experienced the ill-effects of colonisation, it is likely that the difference in rates between Māori and Pākehā can be seen as the transposition of social inequalities upon the biologies of these two populations (Farmer 1997b:429, Goodman and Leatherman 1998:5, Ward 1999:1). The relationship between social inequality and tuberculosis occurs through a number of pathways, with housing conditions being one. Overcrowded, poorly ventilated and dark housing conditions are common among marginalised populations, and there is evidence that housing conditions were more often substandard and overcrowded among Māori than among Pākehā (Department of Health Head Office 1957-75, Downey 1946:3-17, Trott 1940:8-19, Wang and Lin 2000:249).

However, while these population-level differences are important and are likely to reflect widespread social inequalities, local level factors were also at play to create differences within these populations. Important differences in housing conditions occurred within the Māori population, and accounts suggest that the rates of tuberculosis also varied between Māori communities, households and individuals (Allen and Phillips 1933:55-56, Boston 1948, Dowling and Banks 1943:56, Simpson 1940). My interest in the concept of local biologies (Littleton 2007) within the Māori population was sparked by contemporary eye-witness descriptions by medical students doing their final year dissertations in the Rotorua region in the North Island of New Zealand in the 1940s (see Dowling and Banks 1943, Simpson 1940). They contrasted the health and housing conditions of Māori living in the predominantly rural area surrounding the urban centre of Rotorua city, with two kāinga (Māori-style settlements)1, Whakarewarewa and Ohinemutu, within Rotorua city (Figure 2). The authors of these studies concluded that the health of the kāinga residents in the urban centre was better than that of their rural neighbours. Simpson (1940) based his analysis on numbers of Māori from the two areas who were hospitalised for various diseases, and found that a higher proportion of those Māori hospitalised for TB came from the surrounding rural area. For instance, he found that in 1936, 83% of Māori hospitalised for TB came from the surrounding rural area (Simpson 1940). While his conclusions would not be seen as conclusive today - we would need rates and age-standardised ones at that - it seems likely that Simpson was seeing a difference, as his data was not just based on cases, but on other observations and discussions with very well-informed district health nurses. Further support for this difference is also supplied by a slightly later dissertation. Dowling and Banks (1943) examined 15 schoolchildren from Whakarewarewa who had tested positive in the Mantoux
test. They found that these children had a lower incidence of tuberculosis (4.4%) than was indicated by a 1935 study by Turbott of rural Māori on the East Coast of the North Island, which found that 12% of Mantoux-positive children had tuberculosis. Taken together, these lines of evidence do suggest that a health differential between the urban and the rural Māori residents was observable by well-informed people who had first hand knowledge of the area.

Figure 1  Map of New Zealand, with Rotorua indicated. Photo courtesy of Brian Russo at Entropy.Net.
In this chapter I explore the social inequalities behind the different housing conditions and the subsequent risk of tuberculosis experienced by Māori living in the two areas of the Rotorua region. Through the comparison of these two groups, I demonstrate that focussing upon differences occurring at a population level may mask important inequalities occurring within populations, and that local level factors are an important component of explanations for the occurrence of disease.

The research from which this chapter is drawn took place over one year as the basis of a Master’s thesis. A range of historical and contemporary sources were used, including archived government files, unpublished manuscripts and documents, and published works. These were located at the National Archives and National Library of New Zealand, the Auckland and Otago university libraries and the Taranaki Research Centre, Puke Ariki. There were many more documents than could be investigated within the given timeframe, and documents were selected based on the presence of particular keywords in the title and citation. Because these two areas of Rotorua were not generally viewed as discrete or distinct from each other, comparative data were generally not collected, and are thus scarce. Information is available on either the Rotorua region as a whole or on the two kāinga (Finn 2007:21-27). Thus, the main sources of data for this chapter are the two dissertations written by medical school students in their final year of study at the University of Otago, which investigate the living conditions of Māori people in the Rotorua region (Dowling and Banks 1943, Simpson 1940).
Tuberculosis, housing conditions and political ecology

The biological component of the link between housing conditions and the transmission of tuberculosis infection is well understood (Antunes and Waldman 2001:1071, Clark et al. 2002:940, Krieger and Higgins 2002:758). Tuberculosis is spread via droplet infection, and when produced indoors, droplets can remain in the air for quite some time. Ventilation and sunlight (ultraviolet radiation) are ways to eliminate the droplets. Tuberculosis spreads more quickly in poorly ventilated and dark houses. Overcrowding increases the probability of exposure to the tuberculosis bacillus when an occupant has infectious pulmonary tuberculosis, by causing people to be in closer physical proximity to the tuberculosis sufferer and thus more likely to come into direct contact with the broadcast of droplets from sneezes and coughs. In combination with low ventilation and lack of sunlight, overcrowding also leads to an increased concentration of the bacillus in the air due to a smaller air space per person, which therefore increases the risk of occupants breathing in the bacillus (Clark et al. 2002:940, Iseman 2000:51-58, Wang and Lin 2000:249). Housing conditions determine the spread of tuberculosis infection rather than the development of tuberculosis disease, which can take place some time after tuberculosis infection is contracted. While the movement from tuberculosis infection to tuberculosis disease is determined by factors other than ventilation, sunlight and overcrowding, general housing quality and sanitation are important and can affect this progression. For instance, water-borne diseases such as typhoid are more common where sewage systems and water supplies are substandard, and these diseases weaken the immune system and render it less able to resist infections (Fine 1994:60-61, McDade 2005:503, Roberts and Buikstra 2003:17-19). Thus it is clear that variation on a community, household and individual level is important in influencing the risk of tuberculosis infection and the development of tuberculosis disease.

In investigating the relationship between the biological features of disease and local, national and global factors, the political ecological perspective provides a useful framework (Farmer 1997b:416, Goodman and Leatherman 1998:4). The underlying political economic approach views health and illness as social and political issues where “biologies are affected by and reciprocally influence such factors as the control, production and distribution of material resources, ideology and power” (Goodman and Leatherman 1998:19). Health and illness are seen as the embodiment of oppressive factors, and biomedicine and the prevailing beliefs about health and illness have a role in the creation and maintenance of existing power relations and inequalities (Littleton 2007:135, Singer 2001:93). In a recent article, Leatherman (2006:47) succinctly demonstrates the combination of perspectives in political ecology: “[F]raming biocultural relationships within a political-ecology approach that explicitly connects issues of power and inequality (from political economy) with human–environment interactions (the concern of ecological anthropology), and addresses these relationships at the intersection of the global and the local”. A number of ecological factors interact with the tuberculosis bacillus and the biologies of the individuals affected. Further, this interaction is surrounded by (and, in turn, interacts with) a host of social, political and economic factors (Leatherman 1998:1035). Political ecology is useful in my analysis, as it draws attention to the specific linkages between environments and the biologies of diseases and their hosts.

In this case study, two differing environments are seen to interact with the biology of tuberculosis to create differences in the risk of contracting tuberculosis infection and developing tuberculosis disease. The housing conditions and risk of tuberculosis are discussed for each of the two areas in Rotorua, followed by a discussion of the implications of these differences.
Comparison of the housing conditions and the risk of tuberculosis experienced by Māori living in two different areas in the Rotorua region.

The two kāinga and the risk of tuberculosis among the households

Whakarewarewa and Ohinemutu are two historic kāinga in the city of Rotorua (Edwards 1996:68, 76-78, Lange 1999:35, Waaka 1982:45-46, Waitangi Tribunal 1988:14). The style of house at kāinga throughout New Zealand varied. Some houses were of the Māori style, often made from raupo (bullrush), wood or corrugated iron, with one large room and a door and window at one end. Others were wooden houses built in the Pākehā style, with several rooms and often a verandah (Figure 3).

Figure 3  Māori and Pākehā style houses, circa 1890, Parihaka Pā. Photo courtesy of the Alexander Turnbull Library (Burton Brothers (Dunedin) 1868-98 ca. 1890). (Permission of the Alexander Turnbull Library, Wellington, New Zealand, must be obtained before any re-use of this image.)

A range of housing conditions was present at the kāinga. Before the 1920s, the housing conditions were generally substandard, with overcrowding, poor ventilation and dampness common. An improvement took place during the 1920s. In order to understand the history of housing in the two kāinga, I provide a discussion of the tourist industry and the relationship between the residents and the government. In the early 19th century, traders and missionaries first came to the Rotorua region, and a tourist industry began to grow in the region in the mid-19th century. The primary attractions were Māori performances, the geothermal activity (Figure 4) and the Pink and White Terraces (a natural set of hot springs and silica terraces arising from volcanic processes, which were widely held to be one of the ‘wonders of the world’) (Edwards
1996:77). Hotels were built, and Māori living at Whakarewarewa and Ohinemutu quickly developed entrepreneurial initiatives selling food, guiding groups of tourists around the area and providing concerts (Edwards 1996:77, McKenzie et al. 1926:4, Tapsell 1972:87, 89). In 1880, it was decided that a town should be built at Rotorua, around the tourist attractions and the kāinga, and development commenced in 1882 (McKenzie et al. 1926:4).

Figure 4  Pohutu geyser in Rotorua, 2005, an example of the geothermal activity. Photo from private collection.

The two kāinga were the focus of (often unwanted) government intervention for quite some time. While the residents were focussed upon improving their living conditions and wanted to retain control over their resources, the Department of Tourist and Health Resorts, and other governing bodies, wished to absorb the two kāinga into the national tourism infrastructure (Waaka 1982:79).

Some efforts had been made during the early 20th century to improve the conditions at the kāinga, initiated and funded by the Town Council. However these were of a superficial nature, such as installing streetlamps and building roads. The Engineer in Charge of the Rotorua area was critical of their efforts, saying: “in a most disjointed manner…the late town council and town board only acted when actually compelled to do so” (Tourist and Publicity Department 1907-09).

The occupants and the Department of Health had been making complaints about the housing conditions at Whakarewarewa and Ohinemutu for quite some time (McKenzie et al. 1926:5-6). However, it seems that only when complaints from tourists began to increase in the early
1920s, was the government finally compelled to set up a commission of inquiry to investigate what improvements were needed, and to make recommendations as to whether ‘model Māori villages’ should be set up at the kāinga (McKenzie et al. 1926:1). Based on the recommendations of the 1926 final report from the commission, it was decided to turn the kāinga into ‘model Māori villages’, and the improvements in housing conditions discussed above are the result of these efforts (McKenzie et al. 1926:9).

The government would invest in improving living conditions in areas that could be, or currently were, attractive to tourists, and these then became ‘model Māori villages’. Māori would continue to live there and entertain tourists, thereby attracting more tourists and tourist revenue. There were mixed opinions about these villages: Apirana Ngata, a prominent Māori lawyer and politician, felt that they were degrading, but they were seen by other Māori as an opportunity to improve living conditions and to earn an income (McKenzie et al. 1926:9-10, Corbey 1995).

As a result of the recommendations of the commission, older houses were torn down and new houses built, while other houses were repaired. The new houses were built further away from each other and on drier patches of ground, so that dampness was decreased and ventilation and sunlight increased (McKenzie et al. 1926:10, Simpson 1940). Overcrowding had reduced somewhat by 1940. In 1931, at Whakarewarewa there were 39 houses for 300 people, an average of 7.7 people per house, and in 1940 there were 50 houses with an average number of 6 people per house. The water for the two kāinga came from the town water supply, so was available for cooking and drinking, and there was also a clean supply of cold and hot water from the streams running through the kāinga. A sewerage system was installed in 1935 (Simpson 1940). Thus, the risk of water-borne infections, which reduce resistance to tuberculosis, was minimised.

However, despite the housing improvements, many of the new buildings were still deemed to be overcrowded (Simpson 1940). One example was a new, well-kept but small house occupied by four adults and five children. The size of the house amounted to 230 cubic feet of airspace per individual (Dowling and Banks 1943:14). At the time, 450 cubic feet per person was the minimum accepted by the Department of Health (Ferguson 1994:53). Ventilation also varied, but it was found that in both the older houses and the newer ones it was lacking in half of the cases seen as the windows would often be kept shut. Broken windows in both old and new dwellings were expensive to fix and so would often be covered with sacking (Dowling and Banks 1943:16).

Despite the government’s claims that the investment in the two kāinga was to improve both the health of the occupants and the attractiveness to tourists, it appears that the main priority was attracting tourists in order to increase revenue. This is supported by the observation made by Dowling and Banks in their dissertation that a house which was away from the main tourist area was overcrowded, dilapidated, and had not been connected to the water supply or sewerage system, while houses closer to the tourist track had been improved (Dowling and Banks 1943:15). The response of a local Health Inspector to letters to the editor of The Rotorua Times complaining about the living conditions in 1910 is particularly telling. He wrote to the Minister of Tourist and Health Resorts to say that he carried out an inspection the day before and had found no cause for concern because: “Not one tourist in a hundred ever sees any human excreta as there is none within view of the public paths” (Tourist and Publicity Department 1909-34). This account suggests that the conditions of the areas which were away from the public view were not as important as those that were visible to tourists.
Income is also an important factor when considering housing conditions. The rate of pay for the types of work generally undertaken by Māori living at the kāinga (typically in forestry and farming) was at or slightly below the average weekly wage for New Zealand, although for some work, such as market gardening, wages were very low, at one shilling per hour (Dowling and Banks 1943:24, New Zealand Registrar-General’s Office 1946:571). Most Māori living at the kāinga worked in jobs where the wages were sufficient and regular. They also had opportunities to supplement their income from the tourist industry, through concerts, guiding, selling food, and so on (Figure 5). During the high season for tourists, guiding could provide an income equivalent to the average weekly wage for New Zealand. Reports suggest that the income of most Māori living at the kāinga was sufficient for them to be comfortable.

Figure 5  Māori guide and tourist at Whakarewarewa, 1908. Photo courtesy of the Alexander Turnbull Library (Price ca. 1908). (Permission of the Alexander Turnbull Library, Wellington, New Zealand, must be obtained before any re-use of this image.)

Thus, it is clear that a combination of government assistance and improved income opportunities had a positive effect on the housing conditions of Māori at the kāinga. However, the investment of government into the two kāinga was patchy and incomplete and focussed on the appearance to tourists rather than improving standards of health. The level of overcrowding and access to sanitary conveniences were dependent on the location of the house in relation to the paths taken by tourists, and thus their utility to the tourist industry.

The rural area and the risk of tuberculosis among the households

Information about the rural areas surrounding Rotorua is scarce; however it is known that tracts of land were uncultivated, while others were used for subsistence or income-generating farming by family groups or individuals (Simpson 1940). In general, the housing conditions of the surrounding area were of a standard below that found in the two kāinga. The materials were more frequently of a lower quality, such as corrugated iron, and the houses were often
dilapidated. They were observed also often to be overcrowded as they were small in size. They frequently had little ventilation (although were sometimes draughty) and little sunlight due to windows being covered with boards or sacking. The water supply for the Māori homes in the surrounding areas was often from streams or wells and was not filtered or sanitised. The sewerage was generally dealt with using long-drops (outside pits), or sections of bush which could run off into streams and wells (Simpson 1940). Thus, the risk of tuberculosis was likely to have been higher for those Māori living in the area surrounding the kāinga, both directly through overcrowding and reduced ventilation, and indirectly through the effects of water-borne diseases.

Māori in the surrounding area faced many of the issues experienced by rural Māori throughout New Zealand. The income from farms was often low and inconsistent, and casual work was taken up to supplement the family income (see Hohepa 1964:67, Simpson 1940). Simpson (1940) notes the problems many Māori faced in keeping their farms maintained due to financial difficulties. If the farmers became ill they were reluctant to stop working because they would lose money as their plots of land and animals would deteriorate.

Land development schemes (designed to develop land into farms which Māori would then run) began in 1931, and between 1931 and 1940, the lands surrounding the two kāinga in Rotorua had changed from largely uncultivated tracts of land to farmland (Simpson 1940). Reports suggest that the schemes were seen as positive by local Māori, and that many were attracted to them because of the opportunities they offered for occupational training, income and the potential to eventually own a farm (Ngata 1940:145, Simpson 1940). The schemes provided employment for Māori from both the central kāinga and surrounding areas. However, there was a selection process, which tended to exclude those who were most marginalized, and the number of Māori that the schemes supported was limited. The schemes provided new homes with good ventilation and sunlight, lots of windows and room for cross ventilation. However, accounts suggest that the houses built for Māori by the government were often too small for the families which occupied them as the amount of funding available was dependent upon the ability of the borrower to repay. The families in the schemes often struggled to repay the costs of development (Downey 1946:3-17, Kwe 1946:120-127, Department of Health Head Office 1935-41).

A related issue is the inaccessibility of housing loans offered to Māori. Dowling and Banks (1943:17) note that, although housing assistance was given to Māori who had security, this was not of help to the majority of Māori living in the surrounding district as they generally did not have assets they could use as security. For those who could access the loans, the houses built were again often too small, which encouraged overcrowding, and thus may have increased tuberculosis transmission (Department of Health Head Office 1935-41). These wider national forces played out in different ways on a local level and resulted in differences in housing quality.

Thus, it is certain that overall, Māori living at the kāinga were financially more secure than those living in the surrounding areas. Also, the living conditions in the surrounding area were, overall, substandard as compared with the two kāinga. However the picture is somewhat more complicated than this as some Māori living in the rural area had the opportunity to improve their housing conditions through housing loans and the land development schemes. Also, some Māori living at the kāinga continued to experience substandard housing conditions because they were away from the tourist areas and did not receive government assistance. This further helps to demonstrate that local factors are important in understanding the occurrence of tuberculosis. It is also demonstrated that these local factors are intertwined with national and international factors which play out in different ways. Together, these factors influence overcrowding and lack of sunlight and ventilation, which are in turn related to an increased probability of the transmission of tuberculosis infection.
Discussion

This chapter demonstrates that discussing differences in rates of disease at the level of ethnicity may mask the differences and inequalities within populations. While the overall rates of tuberculosis were higher and the standard of housing lower for Māori as compared to Pākehā, important differences occurred within the population and these differences reflect the local economy, demography, politics and history. Also, in demonstrating that the risk of tuberculosis not only varies between ethnic groups, but also varies at community, household and individual levels, this chapter challenges the use of the notion of ‘race’ as an explanatory variable for infectious disease.

There is some evidence that Māori living in the two geographical areas in the Rotorua region differed in their health status and that those living at the kāinga were in a better state of health in general. Overcrowded, poorly ventilated and dark housing conditions were present to a greater extent in the surrounding rural population than among Māori living at the kāinga. The general housing conditions were also substandard as compared with those of the kāinga, which increased the probability of comorbid infections, and thus the activation of tuberculosis disease as a result of weakened immune systems. While inequality and differential access to resources is seen in the comparison between Māori living on the kāinga and Māori living in the surrounding areas, differences can also be seen within the communities. Those Māori living in the kāinga in houses which were invisible to tourists were not provided with the same assistance as those living along the tourist trail. Many Māori living in the rural areas did not have access to the assistance provided by the land development schemes and did not have the security required in order to take out a loan.

While local factors are key in explaining differences in rates of disease, it is important to situate these factors in relation to national and global level forces. For instance, international tourism, operating at a global level, was a key factor in driving policies and their implementation. The national level issue of government interest in the tourism industry clearly influenced the housing conditions and health status of Māori in the Rotorua region. Colonisation, land alienation and the resultant landlessness of many Māori are other important factors within which local disparities must be situated.

This example is of interest not only for the historical information it provides, but also for its historiographical significance. The two kāinga were of particular interest to government because they were involved with the tourist industry, while the people in the surrounding area were of no special interest to government. This is likely to explain the fact that more information was collected and stored which pertained to Māori living at the kāinga. Much more is known about these people, while relatively little is known about the Māori people of the surrounding rural area. This demonstrates that the marginalisation of particular groups in society is reflected in the marginal amounts of information about them that is collected and stored.

Local factors are thus vital in the investigation of the ecological relationships between social inequality and tuberculosis. The importance of local factors can be observed through the differences between the health status of Māori in two areas of the Rotorua region and the households and individuals therein. The variation in these factors can be tied to issues such as global trends, relationships with central and local governing bodies, history and geography, visibility, and economic situations. It is argued that these differences can help to explain differences in rates of tuberculosis through their interaction with housing conditions and ultimately the process of tuberculosis transmission and progression.
References


Burton Brothers (Dunedin) 1868-98, ca. 1890. European style meeting house Miti Mai Te Arero, also known as Te Whiti's House, at Parihaka. Collection: Original photographic prints and postcards from file print collection, Box 7 (PAColl-6001). Alexander Turnbull Library: PAColl-6001-48.


Tourist and Publicity Department, 1907-09. *Rotorua township, Native Affairs re land regulations, rating and sanitation*. Archives New Zealand / Te Rua Mahara o te Kāwanatanga, Head Office, Wellington: AECB 8615 TO1 (1902/43/3 box/item 31).


Notes

1 A kāinga is a settlement with a central communal area, or marae, surrounded by houses occupied by extended families.

2 See Finn 2007: 21-27 for further information on the data collection process.
Part 3: Living with Tuberculosis

Introduction: Living with Tuberculosis

“The everyday life of TB” section includes one historical and four contemporary studies which focus on individuals, families and communities dealing with tuberculosis in their everyday lives. Deborah Dunsford’s case study of TB in 1940s New Zealand illuminates the multiple dimensions of TB at that time and also provides a searchlight probing into the future. Sixty years later, in urban Auckland, the complexities of everyday experience with tuberculosis and the patterns of social division it both marks and creates show strong correspondences with the past.

There are changes, of course. Drug therapy in the community has largely replaced long stays in the isolated but companionable sanatoria; the middle classes no longer figure in TB statistics and, partly in consequence, TB is no longer a rallying point for collective action.

But the continuities are striking: there are still major disparities between Maori and Pakeha rates, between the poor and the affluent, with a particular focus on housing (see Finn, this volume). Immigrants are still blamed for bringing in TB and consuming health service resources, although who the immigrants are changes over the decades: British, European, Pacific peoples or Asian and African. For many, TB is a stigmatised and stigmatising disease. For some, there is no complete recovery and TB is understood in a variety of ways, sometimes as incurable and fatal. TB still exposes the fault lines of society and the operation of prejudice. It has the potential for division: within families, within communities and neighbourhoods and within the nation. TB is used to blame and exclude marginal others. The involvement and use of the media calls for a delicate balance between raising awareness and frightening people or re-stigmatising those with TB. Tensions between biomedical approaches and public health approaches still continue, and then, as now, both require resources. But in the mass media scientific technologies rather than community public health work remain the main repository of hope for the future (Lawrence et al. 2008).

As Dunsford’s chapter describes, it was the hope of mass X-ray, even in the absence of effective treatment that supplied this optimism. In an early remarkable moment of bi-cultural partnership in community action the Taranaki Mobile X-ray Unit led the way in the 1940s to what became a national campaign in the 1950s. The alarm raised about TB which galvanised communities into action was related to the war effort: part of the complex relationship between the armed forces and medicine that Padiak (this volume) explores in detail.

The experience of Sonia Davies who likely contracted TB in the 1940s while nursing, introduces Alison Searle’s study of Pakeha and tuberculosis, set in Auckland in 2003. While Pakeha TB rates are less than 2:100,000, because they are the dominant population Pakeha notifications comprise about 10% of the total per year. Searle shows how the popular link between TB and others (migrants, poor people) makes a diagnosis of TB shocking for many Pakeha. She, like the other contributors to this section, makes use of theories of stigma to understand and convey to the reader the multidimensional exclusionary experience of having TB as a Pakeha.

While the experience of stigmatising processes is common in all the contributions to this section, the nature of the processes and their content varies from one community to another and from one individual to another. Anneka Anderson explores how the majority of her participants who were migrants to Auckland from India, Korea or China, managed their presentation of self by severely limiting the disclosure of their TB status. They feared
rejection from within their family or community as well as from other New Zealanders. She canvasses the association of TB with infection and death as well as with wrong conduct or character flaws. As both Jody Lawrence and Roannie Ng Shiu et al. observe for the Somali and Pacific communities in Auckland respectively, the effects of non-disclosure can severely limit the social support available to individuals or families with TB.

Lawrence challenges the assumption that screening on arrival will resolve infectious disease issues of those arriving in New Zealand from high incidence countries. In her study, she focuses on how the migratory journey and the conditions of re-settlement, in conjunction with exposure to TB, may give rise to elevated rates of TB disease in New Zealand. She focuses on the multiple losses that Somalis, who are almost entirely from refugee backgrounds, have experienced and continue to experience in New Zealand, despite their active efforts to build their community and care for themselves and their families both in New Zealand and in the Somali diaspora. She shows how Somali people connect these losses with their poor health: yet another loss.

The experience of displacement felt so keenly by people of refugee background is also felt by other migrants, including those from Pacific Islands who participated in Ng Shiu’s study. It was manifest in the challenge of dealing with both New Zealand and Pacific health systems and knowledges, in accommodating to the idea of TB in New Zealand being curable, as well as coping with the difficult living conditions many Pacific people experience in New Zealand, especially with poor and overcrowded housing. As a result, the TB rates among Pacific people and Pacific young people in New Zealand are high, often higher than they are in their home islands. This surely is a “call to arms” for communities which could well emulate Maori and Pakeha in Taranaki who worked together so effectively in the 1940s.

These New Zealand stories raise issues that are shared with Canada and other wealthier nations. They remind us that successful TB control and treatment is based on an understanding of the past and contemporary terrain, as Porter and Ogden (2002) pointed out in their discussion of the “how” of care. They argued that the often-forgotten human values of human relationships, partnership and care are the basis for success and that “Engaging with what it is to be human, and applying it to our work, scholarship and relationships with each other, with patients and with communities, may be the easiest breakthrough yet in public health…” (Porter and Ogden 2002:398). As many writers on tuberculosis and migration have noted, these relationships of care need to extend beyond national borders and to groups which may be within national borders but which are clandestine, undocumented or socially marginalised (Enarson 2006:945). TB can be very divisive: within families, within nations and between nations. Yet it is no respecter of borders, and multiplies along the lines of social divisions. The work of TB control requires cross-national and multi-disciplinary strategies as well as local efforts to change those complex ecologies that currently give rise to TB.

References


Notes

1 Pakeha is a widely used Maori term for New Zealanders of European descent.
Chapter 14

The Bright Light of Action and Hope: Illuminating the Complexity of Tuberculosis in New Zealand in the 1940s

Deborah Dunsford

In the 1940s, New Zealand shared in an international wave of professional and public optimism that tuberculosis would soon be firmly under the medical profession’s control (Bryder 1988:226-239, Bryder 1991:85-87, Daniel 1997:41-48, Dow 1999:195, Feldberg 1995:176-181, Fitzgerald 2002:208-218, Jones 2001:191-218, Lerner 1998:34-55). This atmosphere of hope did not arise from an available drug cure but was based in New Zealand largely on the diagnostic technology of mass X-ray and an increasing expectation that successful drug treatment would be found soon. The availability and early results of mass X-ray screening were the driving forces behind a systematic public health assault on TB which in turn raised the public profile of the disease. The war on TB was the major public health concern of the day, indicating the significant threat it still represented across all strata of New Zealand society.

This paper argues that the flow of action on and publicity about TB before effective drug treatment was available meant that the 1940s can be viewed as a crucible in which the complex web of social issues associated with tuberculosis was unusually illuminated. Factors such as the disparity between Maori and European New Zealander incidence and death rates, the role of poor or overcrowded housing, the growing recognition of the stigma often felt by those with the disease and the identification of immigrants as unwanted carriers of TB were all examined in the public arena at this time. There is some incongruity in the fact that this wider discussion and awareness of the social nature of TB occurred just before effective drug treatment largely removed New Zealand’s middle classes from the TB equation in the 1950s.

The catalyst of war and X-ray technology

X-ray technology had been available for some time but World War Two provided a new incentive to use it on a broader scale for TB screening work. Determined to avoid the high rates of TB amongst soldiers that had occurred during World War 1, the New Zealand Government took preventive action and introduced X-ray screening of all military recruits to ensure those with or susceptible to TB did not make it into the armed forces. The results of screening this one sector of the population flowed through to the country’s TB statistics. The Health Department’s Annual Report for the 1941-42 year showed a marked increase in all forms of TB in males, mostly from the military service age group. There was no matching increase in female TB. This signal that the numbers with TB in the population were probably much greater than previous statistics had indicated was cause for some alarm, although the potential of mass X-ray as an inexpensive and effective method of identifying such dangerous ‘unidentified cases’ counterbalanced this, and the promise of extending the new screening technology to the rest of the population was also acknowledged. In the continued absence of a cure, the surge of optimism and activity based on the potential of mass X-ray diagnosis owed more to hope than reality. However, the combination of wartime action and growing optimism created political and public support for anti-TB work and lead to the creation of a specialist Division of Tuberculosis within the Department of Health from 1943. Such a division had been a recommendation of the 1928 Committee of Inquiry Report into the Prevention and Treatment of Pulmonary Tuberculosis in New Zealand but had not been acted
on until this time. The work and singular focus of this Division and its staff \(^5\) became the driving force behind the intense and centralised anti-TB activity that characterised the rest of the 1940s. From mid-decade, reports of possible drug treatment for TB were also being received, fuelling the underlying sense of optimism still further.\(^6\)

The problem of tuberculosis among Maori

The high tuberculosis rates among Maori were a focus of particular attention during this period. The excessive Maori tuberculosis burden had already been indicated by Dr Harold Turbott’s East Cape studies in the 1930s \(^7\) but the more comprehensive collection of data that occurred from the early 1940s confirmed high Maori TB rates across the whole country, as well as signalling that a high proportion of Maori cases remained dangerously undiagnosed.\(^8\) In 1942, New Zealand’s European-only TB death rate was 39 per 100,000 while the Maori rate was 422 per 100,000, one of the highest TB death rates in the world.\(^9\) Even before the Tuberculosis Division began its work in 1943, the publicity about such high Maori rates had generated public and professional concern and some action. The most dramatic initiative to tackle Maori TB was the Taranaki Mobile X-ray Unit, a project widely praised as an example to all \(^10\) and illustrative of the great hopes radiography represented. There were significant regional variations in New Zealand TB rates and the rural, dairy farming region of Taranaki in New Zealand’s North Island had been shown to have an extremely high level of TB compared to other infectious diseases particularly amongst Maori.\(^11\) In mid-1941, members of the Hawera Hospital Board approached the Taranaki Maori Trust Board to promote the possibility of urgent and co-operative action on the matter of Maori TB. Elders on the Taranaki Maori Trust Board, eager to improve their people’s health and needing little convincing of the gravity of the situation, promised a grant of £2,200 for what would be the first mobile power X-ray unit in the country and a remarkable example of bi-cultural co-operation.\(^12\) The New Zealand Government funded a further £2,200 and the four local hospital boards combined to meet the ongoing running costs.\(^13\) The respect shown by Government and the joint hospital boards towards Maori protocol and sensitivities throughout the six years of the Unit’s operation\(^14\) can be seen as both recognition of the significance of the Taranaki Board’s grant and as evidence of an intense and common desire for the project to succeed in lowering Maori TB rates and, by extension, total New Zealand TB rates. The Taranaki Mobile X-ray Unit finally began its work in 1946, travelling not just to Maori settlements but also to the province’s town centres, schools and hospitals with the goal of screening all the people of Taranaki, Maori and European.\(^15\) The Unit was regarded by the Department of Health as a valuable pilot scheme\(^16\) and was eventually absorbed into the operations of the national mass X-ray campaign in 1952.\(^17\)

Social hardship and tuberculosis

The Taranaki Mobile X-ray Unit’s work also brought the increasingly-acknowledged links between social and economic deprivation and TB into the spotlight. In exploring the most effective propaganda to ensure grassroots Maori support for the success of the project, the Unit executive realised that nearly all discussions with Maori about tuberculosis quickly reverted to the central issue of housing. Many Maori held the firm belief that the root of their health problems including TB was the poor and overcrowded state of much of their housing. The Unit executive had no influence over Maori housing conditions but decided to tap into this widely held concern to encourage the highest possible response by Maori to the X-ray screening campaign. It was decided to conduct “a full survey of the social and economic
environment” of Taranaki Maori in conjunction with the Unit’s radiological survey. Maori were especially enthusiastic about the social survey, hoping it would provide the evidence to force central Government to find a political solution to their housing problems. The Taranaki Unit did its best to raise the problem of poor Maori housing with the Government and invited the Prime Minister, Peter Fraser, to the district to discuss the issue. In making the invitation, the Chairman described the efforts taken to establish the Taranaki Unit and cited the particular contribution of poor housing and living conditions to the incidence of TB, warning the Prime Minister that “unless we can tackle and eradicate the cause we will fail in our objective.” The Prime Minister did not visit although a deputation from Taranaki met the Acting Prime Minister, Walter Nash, in January 1946.

New Zealand’s insufficient and decaying housing stock was in fact a nationwide problem the first Labour Government had resolved to address when it came to office in 1935. However, the state building programme was slow, facing war-time and post-war shortages of manpower and building materials (Ferguson 1994:122-137). The public health professionals within the Division of Tuberculosis clearly saw the connections between the need for good housing and a successfully recovered TB patient, Maori or European, and argued strongly that it was cheaper to build houses than TB institutions. Minister of Health, Mr A H Nordmeyer, took on this argument, telling the TB Officers’ 1944 Conference that “in the long run it will pay us even to lose money … if we can build houses for the Maori people, and prevent that very high rate of tuberculosis among them, which reflects little credit on us as their Trustees.”

Ironically, the slow improvements to Maori housing in the 1940s and 1950s were heavily focused on the rural areas just as Maori were migrating to jobs in the towns and cities (Orange 1977:84-98, 179-187, Ferguson 1994:216-222). Many Maori would have left a slowly improving rural situation for overcrowded inner-city suburbs.

Stigma and prejudice

Stigma and prejudice accompanied tuberculosis in the 1940s as in the past. However, the decade also seems to have been a time in which new attitudes were evolving. In spite of the growing medical confidence about detection and successful treatment, many people still felt afraid of the contagion of TB and those with the disease often felt this stigma acutely. In 1944, Dr C H McKenzie of Pukeora Men’s Sanatorium referred to the feelings of many of his patients that their disease was regarded by many with suspicion and, in being sent to the sanatorium, they felt cast out from society. Understandably, the isolated locations of sanatoria might encourage patient feelings that they were living in a form of leper colony. However, oral accounts of sanatorium life also suggest that, although most patients found a couple of friends or acquaintances let their fear of TB show or became conspicuous by their absence, their overall experience was of being supported by family and friends during their illness. It seems that greater prejudice was experienced by people who had been discharged from sanatorium or hospital but were perceived by some members of the community to be an ongoing danger.

An unexpected consequence of TB’s increased prominence may have been that, as the public’s awareness of the extent of the disease became more acute, for many, their knowledge of the nature of TB remained simplistic and even inaccurate. At their 1944 conference, some TB Officers commented that the public had been “overeducated” about TB and most thought it was like scarlet fever or diphtheria, which, unlike TB, developed rapidly and were highly contagious. Some laid the blame for the public’s flawed understanding on the “intensive propaganda” of the Division of Tuberculosis, and its cinema advertising was quoted as a
particularly sensational culprit. The Division found itself treading a fine line between raising informed awareness about TB or creating a state of public alarm about the disease, between encouraging the sick to seek treatment or frightening them into remaining undiagnosed. Public health officials, other medical professionals, TB patients and the public all construed the Division’s messages from their individual perspectives. A letter from “T.B.” to the NZ Herald on 15 July 1948 highlighted this awkward issue of inaccurate public knowledge as well as the role of stigma in discouraging diagnosis:

Whenever an article on T.B. is published the fact that all sufferers from the disease are highly infectious is stressed in every paragraph. This is grossly unfair to those hundreds of patients in sanatoria, hospitals and in bed at home who are not infectious. The average person knows nothing more about the disease than what is read in newspapers and magazines, with the result that T.B. is mentioned in hushed tones and people suffering from it are regarded as untouchables. Until the people are educated on this point, there will be many cases hidden until too late for fear of social disgrace.

The increasing confidence with which TB was being viewed in medical and public health terms during the decade flowed into concerted attempts to counter public prejudice against TB patients and the consequent feelings of shame and disgrace that many TB patients experienced. While fear and prejudice about the dangers of contact with infectious TB patients were still relatively common, a greater sensitivity to the feelings of TB patients and willingness to publicly challenge prejudice was also developing. The new Tuberculosis Associations saw this as one of their particular roles but, at times, doctors, patients and ex-patients all entered the fray. An exchange in the NZ Herald in 1947 over the Auckland Transport Board’s refusal of a request for disabled ex-servicemen with TB to receive free tram passes saw the Auckland Tuberculosis Association secretary fiercely denouncing the decision as “born of ignorance” and for its inference that such patients were “untouchables”.

The ‘problem’ of immigrants

One group of TB patients was singled out for special disapproval in the late 1940s, illustrating how easily the combination of disease and outsider status could result in a double stigmatisation. Immigration rates surged post-war and, with them, the problem of tuberculosis amongst new immigrants re-entered the limelight for the first time since the 1900s (Bryder 1996:461-464). Immigrants with TB were viewed as unworthy newcomers to New Zealand, a burden on Government finances and occupants of beds that genuine New Zealanders urgently needed. During this time, the public campaign to prevent immigrants with TB entering the country was led by the politicians and medical staff of the Auckland Hospital Board, who felt they were seeing a tide of TB cases amongst new, mostly British, immigrants.

Early in 1949, after revealing that they were treating 20 TB migrant cases, the Auckland Hospital Board called publicly for the Government to ensure all immigrants were X-rayed before departure for New Zealand. Existing immigration procedures meant there were two categories of migrant from Britain: the assisted, who received financial assistance from the New Zealand Government for their fare, and the unassisted, who paid their own way. All assisted migrants were medically examined, although not necessarily X-rayed, before departure. Unassisted migrants underwent no medical examination at all. The Department of Health, responding to the Board’s complaints, stated that it had been working with the British Government to introduce the X-ray of all migrants and explained that the problem was that the recent introduction of the National Health System had reset earlier discussions to zero. The Department of Health appeared rather ineffectual in its handling of this situation.
In the face of ongoing complaints about the situation by the Auckland Board over the next two or three years, the Department’s lack of action left it appearing naively optimistic in its view of the immigrant TB situation. However, it needs to be acknowledged that the Health Department was negotiating the issue not just with British health authorities but also with the New Zealand Department of Labour and Employment. That Department’s immigration goals of increasing the workforce as quickly and cost effectively as possible overlaid the Health Department’s public health aims and resulted in both delays and concessions as a satisfactory compromise was reached.  

The Auckland Hospital Board no doubt bore the brunt of the TB immigration problem. As the largest port of arrival, it accepted the majority of immigrants and, with the largest population in the country, its chest and tuberculosis services were under pressure even without an influx of immigrant cases. Auckland Board members and staff complained forcefully at a Board meeting in April 1949, revealing that 32 immigrants had presented to the Green Lane Chest Clinic in the past 30 months. Ringing the familiar alarm bell of the “dangerous undiagnosed case”, the Board’s TB specialist, Dr Chisholm McDowell, stated that the known immigrants with TB would be just a fraction of the actual number of infectious immigrant cases in the country. His arguments echoed those of the early 20th century; these patients had already endangered fellow healthy migrants, especially babies and adolescents, on the journey from Britain. A further injustice was that, in taking a bed in the country’s overloaded tuberculosis hospitals, they took the place of New Zealanders who, by popular definition, were more deserving of the beds. The rising emotion on the issue was illustrated by the extravagant claim of another speaker that “A disgraceful state of affairs has been disclosed…. [New Zealand] could become the happy hunting ground of anyone in England with illness.”

On the surface the press revelled in these colourful statements but they also presented a more evenhanded view which illustrated a growing understanding of the complexity of the TB problem. The Auckland Star reacted to the gap between the Health Department’s apparent optimism and the Auckland Hospital Board’s pessimism over the immigration question with two feature articles. These calmly identified the many issues involved: the lack of accommodation and treatment facilities, the shortage of nursing staff, the very high incidence rates of Maori and the problem of immigrants arriving with the disease. The editorial acknowledged the interwoven complexity of the issues, but did not support the Auckland Board’s argument that immigrants were a major problem in providing adequate TB services. Instead, it judged the critical factor to be the shortage of nurses which meant available beds remained frustratingly empty. The Star laid general blame on poor decision-making in the past by both hospital authorities and the Department of Health at the same time acknowledging the role of the overall post-war labour shortage.

In an example of the shifting but recurring target the immigration-tuberculosis link provided, the Star’s article also gave Pacific Island immigrants an early appearance alongside English migrants as a TB threat. Poor living standards within New Zealand were seen as a particular issue for them, with one doctor saying: “If they haven’t got TB when they arrive, many of them, because of living conditions and associations are infected afterwards and become non-paying guests of the Government”. The public debate about immigrants with TB in the 1940s provides an acute example of the ease with which a minority outsider group with the disease could for a time become the focus of the entire problem. At the same time, the differing responses seen in the immigrant debate indicate the shifts in understanding and attitude towards TB that were occurring.
Conclusion

The 1940s saw an all-out attack on tuberculosis and increasing optimism that it could be eradicated. While the catalyst of World War 2 and the availability of mass X-ray technology produced both action and hope, the political platform on which this was possible was the threat that TB still posed to all strata of New Zealand society. In spite of all the activity during the 1940s, the results of TB treatments remained arbitrary and it was not until the triple drug therapy of the 1950s that the random nature of TB ‘cure’ ended and incidence plummeted.

During this time of intense activity, the bright light generated by such a society-wide threat revealed the very complexity of the problem of tuberculosis. The social drivers of poor and overcrowded housing, specific ethnic risks, the stigmatization of TB patients and the double stigmatization of immigrants with TB were unusually exposed and increasingly understood in the 1940s. The decade marked a high tide of public concern about TB but, as the spotlight revealed the complexity of the problem of TB, drug treatment would soon remove the problem for most.

As drug treatment eradicated the TB threat for the majority, the spotlight resulting from their collective fear that had so effectively illuminated the social complexity of TB dimmed. Up until the end of the 1940s, TB was common at all levels of society and social factors were a common but not essential feature of individual TB cases. But by the early 1960s, TB was becoming increasingly invisible and irrelevant, little more than a rapidly fading memory for the vast majority of New Zealanders. It can be seen as paradoxical that the wider community’s awareness of the disease and its social complexity, such a feature of the 1940s, diminished at the very time that social factors rather than contagion became the most significant aspect of TB incidence.

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Chapter 15

Pakeha and Tuberculosis in New Zealand: Not the “Other”

Alison Searle

I knew Dad was terrified that I might transmit the disease despite the fact that 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).

Historically TB has been a stigmatised disease for Pakeha as this quote from the memoirs of former MP Sonia Davies indicates. She was believed to have contracted TB while nursing TB patients in the 1940s. The experiences she describes indicate attitudes based on a theory of contagion (and associated fear of mortality), and show that, for Pakeha, even among close family members, the stigma of tuberculosis prevailed and continued long after the infectious period. As this article shows, sixty years on these attitudes and the associated stigma continue to feature in the experiences of Pakeha tuberculosis sufferers.

While Pakeha make up 80% of the population in New Zealand, they have the lowest incidence of tuberculosis disease, with most cases occurring in the elderly (those over 70 years). In 2003, there were 41 Pakeha people notified with TB disease (1.6/100,000) out of a total of 418 cases for New Zealand (11.2/100,000) (ESR 2004). Given their dominant position in New Zealand society, a diagnosis of TB and the subsequent treatment process can represent an extraordinary “othering” for Pakeha – one shaped by the experience of stigma. This article explores the experiences of these Pakeha “others”, adopting an historical perspective that highlights continuities and changes in stigma, while also showing how TB is experienced and responded to in a variety of ways within this group.

The classical theory of stigma was developed by Erving Goffman (1963) from an interactionist perspective. According to Goffman, the process of stigma spoils the identity of the individual concerned who is devalued from without and within so that the “whole person is reduced to a tainted and discounted one” (Goffman 1963:12). Many of us will get to experience both roles of this fluid process depending on varying temporal or socio-cultural contexts (Goffman 1963:144).

At a collective level, the social processes of stigma operate as a means of social exclusion of those considered unworthy. However the essential role of power inequities that are a precursor to stigma processes are made clear in the following definition offered by Nancy 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).

The social process of stigma can affect TB patients, their friends and families adding significant social and emotional stress to the burden of illness which continues long after the tuberculosis is considered to be cured (Macq et al 2006:347). Experienced stigma also has implications for managing TB treatment, commonly leading to a delay in diagnosis, causing
more of the patients’ contacts to be exposed to the TB bacillus and for the disease to progress to an advanced state before being treated. If the distress caused by stigma is oppressive then treatment may be abandoned or used in an ad hoc manner, meaning medication is less likely to be effective. The experience of the stigma of tuberculosis varies across and within cultural groups and is also influenced by the social standing of the sufferer. The study of stigma in relation to TB can give an indication of the effect of treatment practices on patient stigma and the variable manifestations of stigma for TB sufferers, allowing health workers to manage patient treatment with sensitivity. An elaboration of the stigma experienced by Pakeha adds another perspective to the recent contextual study of tuberculosis in New Zealand (Ng Shiu 2006, Oh 2005).

Research participants and methodology

My research with Pakeha tuberculosis sufferers took place in 2003. This research formed the basis for a Masters thesis in social anthropology (Searle 2004), and was undertaken as part of the Political Ecology of Tuberculosis in New Zealand project. Nine participants who identified as Pakeha and had recently suffered from tuberculosis disease were recruited with the assistance of Public Health nurses. Eight of these participants were under treatment during 2003, and one had undergone treatment in 1997. All have now successfully completed treatment. The age of participants ranged from 46 to 75 years. They came from an array of socio-economic backgrounds – from an unemployed person living in a run-down boarding house, to a high-income professional who convalesced on a tropical island, flying back for outpatient appointments! Four of the participants had a reactivation of old, healed tuberculosis disease, having initially received treatment soon after World War II. The remaining five participants were experiencing their primary infection in mid-life.

My research included two to three semi-structured interviews with each of the nine participants in a place of their choosing – usually their home or workplace. I also shared transport to clinic appointments with patients when possible, and the discussions that occurred during those times provided a rich background for understanding what participants were experiencing when “going to see the doctor”.

My interviews with participants were designed around ascertaining explanatory models of the illness experience. This approach draws on the work of Kleinman, who describes such models as “notions about an episode of sickness and its treatment that are employed by all those engaged in the treatment process” (Kleinman 1980:106). These models are useful to elaborate the different meaning an illness holds for health practitioners and their patients. Explanatory models are based on a culturally informed understanding of the perceived cause of the illness, why it started when it did, and the history and effects of illness and its treatment. When transcribing and analysing these interviews I looked particularly for themes around the illness experience, with stigma emerging as the most pervasive of these. The subtleties of the stigma process were illuminated for me through several readings of *Stigma: Notes on the Management of Spoiled Identity* by Erving Goffman (1963) in conjunction with interview transcripts. Aspects such as “disclosure” and “passing” discussed by Goffman 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 came to understand that the inherent coping mechanisms of the stigmatised individual make them expert at covering the manifestations of stigma. To identify the manifestations of stigma experienced by individual participants I had to become a better and better detective. While these details were contained in the interviews alone, I argue that they must be situated at a broader structural level for us to
understand vulnerability and support resistance factors. It is important for health professionals to appreciate the social burden that a stigmatised illness like tuberculosis attracts so that they can offer support, understanding and an individualised, flexible approach to patient care. A trusting relationship between caregivers and patients has been shown to assist patients to adhere to tuberculosis treatment that is often long and difficult (Searle, Park and Littleton 2007).

Stigma is a complex phenomenon and its impact on the identity of the stigmatised person varies depending on the social meaning the disease holds for them. To mitigate the effect of stigma, people employ multiple (often unconscious) strategies for dealing with it that are not homogenous. The following sections describe the effects of stigma for a range of study participants, showing the multiple discursive appearances of stigma.

Managing stigma, managing information

People manage stigma by controlling the information they release about their illness. When others are unaware of their “failing”, the stigmatised individual must decide whether to “tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case to whom, how, when, and where” (Goffman 1963:57). Sixty year old Debbie described her reaction to her diagnosis of TB:

… 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] that I’d known for years in the pharmacy to know, but... she [the nurse] took me to all my appointments and I was offered household help and everything …

Debbie dreaded that nurses would make the tuberculosis ‘visible’ by arriving at her home in “crisp white uniforms”. However their car was unmarked and they wore “nice bright clothes”. Their support helped her to ‘pass’ as ‘normal’. Similarly when people inquired about her splint she staged the information to others by describing her extra pulmonary TB as a “bone infection” because that condition carried appreciably less stigma.

Courtesy stigma

Even in an individualised society such as New Zealand a “courtesy stigma” operates, so that “problems faced by stigmatised persons spread out in waves of diminishing intensity” (Goffman 1963:43). Although Debbie did not recognise the stigmatising effects of the disease for herself, she was frustrated by her daughter’s ongoing anxiety that the diagnosis should stay ‘in house’. The relationship between Debbie and this adult daughter had been under constant strain throughout Debbie’s prolonged illness, particularly after Debbie chose to share her diagnosis with a neighbour. People who have familial or other social connections to the TB patient can feel threatened that they too will “share some of the discredit of the stigmatised person” (Goffman 1963:43). The fear of courtesy stigma can cause anxiety for close contacts and lead to strained relations or avoidance.

Sharing the burden

The wife of an elderly TB sufferer sought to minimise the discrediting effect of stigma on her husband and family by drawing my attention to the random nature of tuberculosis. “Well look
at what’s-a-name on Radio Pacific, he’s a very good announcer and he had it and he was in the South Island in hospital for five years”. The fact that it even affected a high-status celebrity meant, for her, that TB could affect anyone.

Normalising the occurrence of tuberculosis or other discreditable conditions can also be assisted by group membership (Gussow and Tracy 1968). In New Zealand the Lung Health Association (former Chest and Tuberculosis Association) began as a charity that included some members who were ex-patients who acted as supporters for TB patients under treatment. This is no longer the case and none of my participants actually continued contact with former TB in-patients, possibly because Pakeha were generally keen to disassociate from a disease they attributed to ‘others’.

Despite their austerity, the sanatoria of bygone days offered TB patients a sheltered world apart, and the sense of belonging and supportive camaraderie is vividly remembered by the old ‘inmates’ that I talked to. In lieu of support by other patients in a live-in facility, Public Health nurses who deliver TB care in the community today act as advocates and confidants with whom patients feel at ease. In the absence of understanding and support to be gained from those who share the stigma, nurses take on the role of “the ‘wise’…the marginal [persons] before whom the individual with a fault need feel no shame…knowing [s]he will be seen as an ordinary other” (Goffman1963:41).

An enduring stigma

While stigma is socially and culturally constructed in the present, historical experiences of stigma also emerged as an important aspect of TB for older participants. Those experiencing the disease for the second time (TB reactivation) offered me a ‘then’ and ‘now’ perspective of their treatment experience. During their first episode of tuberculosis during and after World War II a pharmacological cure had not been around long enough to be widely trusted, and therefore treatment was based on long periods of rest, surgery and isolation in sanatoria. Tuberculosis was then endemic in New Zealand and participants contracted the disease as young adults when there was still a high rate of mortality associated with it. As a result, the accompanying stigma was centred on a fear of a fatal contagion. The contemporary medical management of tuberculosis in New Zealand is currently associated with very good outcomes. However, as we have seen, stigma is still experienced by TB sufferers despite a lower incidence of the disease and an available cure.

Diane contracted TB from her mother, having nursed her up to her death, and remembers the stigma they experienced in the past. When her mother was discharged from hospital, the journey home involved a long bus trip and the travelling party were denied an overnight bed with Diane’s in-laws to break the ride. Diane’s father was so upset by this rejection that a long-lasting family rift developed. Diane went on to explain 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, it’s something that they did in the dark ages, but they’re not, they’re still very conscious of TB.

During her recent episode of TB it was noticeable to Diane that the ‘young ones’ knew less about TB. Even after treatment had ensured she was non-infectious, she found that younger people were fearful of their children being in contact with her. This caused discord within her social network: “it was people on the fringe that panicked”; the older people who had been
around when she first had TB knew that - due to her experience of the disease - Diane would not “do anything that would endanger anyone … she knew how to handle it”. Diane took solace in following good practices to prevent the spread of infection and in having ‘correct’ biomedical education about TB. Her experience and knowledge of TB contributed to her resilience.

**Resisting stigma**

While Diane noticed stigma and experienced some level of disruption to her social network, several participants were not unduly affected by others’ reactions, perhaps indicating a strong self-identity. Frank, a forty-six-year-old, high-income professional stated: “When you tell someone you’ve got TB if they have a problem with it that’s their problem, not yours...that’s your problem, go away!”

Dennis was also 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. Referring to the 1950s he commented:

> 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. He recalls that, when drinking in the pub after discharge, he would tease: “Don’t come and drink with me or I’ll give you TB. When did you last have a chest X-ray? I had one last week!” His attitude suggests that prior experience of TB served to forearm participants second-time around.

**Who is most vulnerable?**

In contrast to the blithe humour of Dennis, Dick (aged fifty) found the stigma of TB exacerbated his already marginal status. He was unemployed and lacked a social network. Having TB added to his vulnerability to social exclusion by others in the boarding house where he lived, illustrating well the contention that health-related stigma is compounded when there are pre-existing conditions of inequity that also attract stigma (Keusch, Wilentz and Kleinman 2006: 257). Even after Dick’s treatment was over, the stigma endured. During Dick’s initial period of hospitalisation for the acute illness phase his fellow boarders were contact-traced and tested, denying him the luxury of managing the disclosure of his diagnosis. Insecurity and suspicion on the part of fellow residents led him to self-isolate; in turn, his isolation led to less and less self-confidence. Sadly, his solution was to use communal areas at night only, eating and watching TV while others slept. Oppressed and marginalised groups who are already socially excluded often have limited capacity to resist other stigma imposed by more powerful groups (Parker and Aggleton 2003:18).

Dick summarised this position well in his own comments:

> 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.
The unhealthy other

While participants’ experience of stigma differed in levels of intensity and effect on their lives, all of them felt, to some degree, in a position of difference. As Scheper-Hughes explains:

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… (Scheper-Hughes 1992: 375).

The “othering” experienced by Pakeha TB sufferers did not equate with their bio-medical knowledge of the disease, rather it stemmed from information about TB received from other sources. Although younger sufferers acknowledged that TB can be successfully treated, for some it was hard to come to terms with having a disease they associated with “outsiders”. David (47 years old) reacted to his diagnosis with

… 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.

In sharing his emotional response, David confronts the question, ‘how could it happen to me’? He could no longer rest assured that TB only happens to the ‘unhealthy other’, members of minority groups he does not identify with. As Goffman notes, “the individual feels ambivalence when he realises who he must accept as his own” (1963:50). David’s explanatory model of tuberculosis was challenged because his Pakeha identity did not offer him a secure boundary from the TB bacillus. He went on to suggest, however, that his TB had been brought from outside, during a visit to India, although he also recalled that while he was growing up he had spent time with his grandfather who had TB. David’s contradictory notions about where he was infected with the disease reveal his ambivalence about having tuberculosis.

Media management of TB

Because members of various ethnic groups may not socialise or work together media images of the ‘other’ carry significant weight in generating ideas that contribute to how we ‘know’ one another (MacPherson and Spoonley 2004:223). The media has a powerful effect on how we define, understand and react to other groups that we have little first hand knowledge of. Ethnicity is frequently the variable that is highlighted in the media to explain disparities between groups within society. A consequence of this is that the combined effects of other categories such as class, level of education or employment status are frequently ignored (MacPherson and Spoonley 2004:223).

In recent years, the New Zealand media have picked up on a barrage of negative statements by a Member of Parliament which portray immigrants as a health burden/risk, particularly in association with TB. 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) have promoted a climate of fear and stigma toward certain immigrant groups in NZ. These stereotypes have been used by the dominant group to stigmatise outsiders (Scrambler 2006:294). The effects of this are very significant, particularly as the paired participants in this study without TB cited the media as their main source of health information, second only to doctors.
An article from the Dominion newspaper (Figure 1) provides a good example of the way in which the media contribute to the image of TB as a non-Pakeha disease. The text of the background article provides a well-written and informative account of a Pakeha solicitor’s experience of TB. However, the picture used to illustrate this is of a Vietnamese man undergoing TB treatment in Hanoi. For those who glance at the newspaper, the equation of Pakeha and TB is not obvious; it is rendered, once again, a disease of the “other”. Pakeha are more often featured as TB scientists, as in the foreground.

**Figure 1** An article from the Dominion Post showing the recurrent association of TB with people of Asian appearance, despite the article’s content.

**Conclusion**

People who suffer from tuberculosis in New Zealand continue to be exposed to the strain of the socially constructed stigma that surrounds the disease. This account of Pakeha New Zealanders’ experiences of tuberculosis has identified the distinctive stigma felt by Pakeha sufferers related to the challenges that ‘having TB’ placed on their identity. Participants and their families employed many strategies to manage stigma, for example by controlling disclosure of the disease when possible, normalising or obscuring the diagnosis or by explaining that they had acquired it outside their usual social circle while travelling in ‘third world’ countries. As members of the dominant group in New Zealand, several participants found this status was challenged when faced with adjusting to having a stigmatised disease.
that they associated with marginalised groups, the ‘unhealthy other.’ The portrayal of TB in
the media has maintained the invisibility of Pakeha TB and supported an association of the
disease with minority groups and immigration. Nonetheless most Pakeha participants were
able to manage or resist the stigma of having TB due to their social class and membership of
the dominant group. However the most vulnerable TB sufferer who had multiple minority
status was powerless to deflect the social exclusion that the process of stigma meted out.
When these issues of unequal power are considered in relation to TB it suggests that
biomedical education about TB will not always be sufficient to counter the enduring stigma
that varies within and across cultural groups.

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Notes

1 The research also incorporated a parallel study of nine ‘well’ paired participants who were matched by ethnicity, gender, age and occupational status. Because people interpret illness through a lens of previously held conceptions of health these (one-off) interviews gave insight into Pakeha health culture and community attitudes to tuberculosis disease.
Chapter 16
Mark of Shame: Social Stigma, Tuberculosis and Asian Immigrants to New Zealand
Anneka Anderson

In many human societies secrecy and stigmatisation are associated with tuberculosis (TB). Disease-related stigmas have significant impacts upon the human experience of illness. Stigma can increase stress associated with illness, contribute to secondary psychological and social morbidity and affect quality of life and physical well-being (Fife and Wright 2000). The aim of this paper is to explore the processes, effects and influences of social stigmas on the diagnosis and treatment of TB in Asian immigrants in Auckland, New Zealand. The study on which this paper is based drew on interviews, participant observation and media analysis. Participants in the research were immigrants from Mainland China, Korea and India. Participants included people who have, or have had TB, family members of people with TB, community members and health care professionals (General Practitioners and Public Health Nurses).

The TB oriented interviews were conducted with 11 people with or recovered from TB to gain an understanding of their experiences with TB, other people’s reactions to their illness and issues surrounding stigma. Interviews with immigrants without TB incorporated a cross section of 12 people from the three ethnic groups and also included family members of TB patients. These interviews were used to assess beliefs about TB and to elucidate how TB-related stigma is created and maintained in each immigrant group. Six health care professionals (three General Practitioners and three Public Health Nurses) were also interviewed to gain an understanding of how stigma influenced health-seeking behaviour, diagnosis and treatment of TB patients.

Stigma

The term stigma was used by ancient Greeks to refer to bodily marks that were designed to expose the moral status of the bearer, signifying that they were a blemished person to be avoided in public places (Goffman 1963). According to Goffman, stigma is still used in a similar sense but is applied more to the sense of disgrace felt than to the bodily evidence of it. He defines stigma as an attribute, an undesired difference that discredits the bearer reducing them from a whole and ‘normal’ person to a discounted, tainted individual who is prevented from full social acceptance. Goffman (1963:14) proposes that there are three types of stigma (that are not mutually exclusive): 1) abominations of the body or various physical deformities; 2) blemishes of individual character such as addiction; and 3) tribal stigma of race, nation and religion. For Asian migrants in Auckland, TB falls under two of these categories. TB can be both attributed to blemishes of individual character and to a tribal stigma of migrants.

Although Goffman acknowledges that stigma is embedded in social and cultural contexts, his studies focus on the individual in an American context and have been criticised as Eurocentric and lacking in discussion of cultural, political and historical context (Becker and Arnold 1986, Predaswat 1992). Becker and Arnold (1986) state it is necessary to use a holistic framework to understand stigma. They further propose that stigma is universal, but notions of what constitutes stigma vary from one society to another due to differing structures, values and cultural norms. This paper supports Becker and Arnold’s approach to understanding stigma and will illustrate the influences of media and social norms on stigma experienced by TB patients.
Tuberculosis: A disease of others

The visibility of undesired attributes is an important aspect of stigma. People construct much of their knowledge of TB and other diseases from media images (Ferreira et al. 2001, Kaperson et al. 2001). Diseases such as meningococcal meningitis, severe acute respiratory syndrome (SARS) and tuberculosis have recently triggered intense media coverage and strong public concerns or “socially amplified hazards” (Kaperson et al. 2001:9). These concerns can generate powerful signals to society that either a new hazard has appeared or an existing hazard is more severe or difficult to manage. By way of example a recent newspaper article recounted:

TB-infected South Korean woman removed at $278,000 cost - Immigration officials spent almost $280,000 to avoid a public health emergency by sending home a South Korean woman who withheld information about her highly infectious and untreatable tuberculosis (New Zealand Herald 2005).

Socially amplified hazards send powerful signals of abnormal risk and negative imagery which generate stigma-related effects for people and places. At the centre of risk-induced stigma is the concept of fear. I argue that media images of TB in New Zealand signal fear of tuberculosis as a contagious disease and portray it as a mark of radicalised difference or a ‘disease of others’.

Tuberculosis has recently become a common topic in New Zealand media. A study by Searle (2004:87) revealed that many media articles falsely associate TB solely with immigration. Media headlines such as “Immigration hunting TB man for overstaying visa” (New Zealand Herald 2003a) and “Migrant worker triggers TB alert” (New Zealand Herald 2003b) have led to a common stereotype held by the New Zealand public that TB is a disease of ‘new immigrants’, not ‘New Zealanders’. Although foreign-born people have higher rates of TB than those born in New Zealand, the notion that TB is exclusively a disease of new immigrants appears to be perpetuated by media reports and editorial presentation.

When groups of people are stigmatised in a society they become labelled or ‘marked’. These labels are socially constructed and create a stigmatised category or stereotype (Crocker and Lutsky 1986). When looking at the context of TB in New Zealand, simply being a migrant becomes a ‘mark’ differentiating them from ‘normals’ through the perceived risk they pose of spreading tuberculosis to the New Zealand public. Tribal stigma was a category that Goffman (1963) used when referring to race, nation or religion where stigma is transmitted through lineages contaminating all members. Although New Zealand migrants are diverse in their countries of origin, language and religion I argue that attributing tuberculosis to migrants creates a socially constructed label, stereotype or ‘tribe’ where all members are seen by the New Zealand public as either contaminated or at risk of contaminating the ‘normal’ others.

Despite mainstream discourse that attributes tuberculosis as a disease of migrants I found that many migrants did not internalise this stigma. Goffman proposed that one of the most important psychological and social components of stigma is ‘impression management’ whereby people create desired images about themselves to control the conduct of others. Impression management can be applied to the management of personal information about the individual or of interpersonal encounters. When I asked participants who had TB where they got it from or those without TB how people develop TB, their responses did not reflect those portrayed in the media. Four participants did not believe that they could develop TB in New Zealand due to the health screening they had undergone before arrival:
Anneka: Do you know of anyone with tuberculosis?
Participant: No, but if you want to come to New Zealand you must have a like a health screen and probably nobody has that kind of thing [tuberculosis]. So I only know [for] my Chinese friends that’s not possible (Chinese man in his 20s).

Like the New Zealand public who attribute TB to the ‘diseased other’, stereotyping also occurs among Asian populations in New Zealand. Four of the participants I spoke to (two Chinese and two Korean) told me that TB was believed to be common among Maori and Pacific Island communities in New Zealand. When asked how they had come across this source of information I was told they read it in newspaper reports. Despite rejecting New Zealand stereotypes or constructing their own, stigma associated with TB for Asian migrants occurs at local, culturally specific levels.

Tuberculosis a disease of contagion and death

Stigma surrounding TB for Chinese, Korean and Indian people is something that is hidden and complex, relating not only to understandings of disease causation and transmission but also linked strongly to social values and religion. On the surface stigma surrounding TB is attributed to fear of contagion and death. Fear is a key concept of how and why stigma persists in many cultures. Coleman (1986:225) suggests that fear surrounding illnesses usually stems from not knowing about the aetiology of a disease (its predictability as well as its course). Most people I spoke to from Indian, Chinese and Korean communities understood that tuberculosis was an infectious disease, and the majority of participants explained to me that people with TB should be isolated from other people to prevent the spread of the disease: “So if someone has, you know, TB, we have to keep away because it can be infectious” (Korean woman in her 50s).

Despite this knowledge, the fear of TB remained because of its moral and social implications. When examining the process of stigma associated with TB among Asian communities it is evident that stigma is expressed both directly and indirectly. Direct forms of stigma are expressed through various social structures such as marriage and household composition. Many participants and health care professionals told me of women who had been divorced when it was discovered that they had TB, or patients turned out from their homes. Eight out of eleven participants with TB did not disclose their TB status or limited their disclosure due to fear of rejection and isolation from family, friends and communities. Meeta, an Indian women in her 30s, who had recently become married, hid her symptoms and delayed seeking medical intervention as she was afraid her husband would divorce her and her in-laws reject her if they knew she had TB. Elsewhere, Rajeswari et al. (2004) found that fear of others discovering their TB status prevented Indian people from visiting friends and family and disclosing their health condition to friends and even their spouses.

Processes of stigma may also be indirect and constitute ‘social gossip’. As many people were aware of my research area, tuberculosis was a popular topic of conversation between community members and myself. Informants would tell me of people who had had TB in the past or who had recently been diagnosed with TB. I was shocked one day to receive a phone call from an Indian woman asking me did I know that another woman (a mutual acquaintance) had been diagnosed with TB. I was surprised because I gained this information from a member of the community before I was informed of the new TB case by health care professionals.
Tuberculosis and infection

Tuberculosis is so strongly associated with the notion of contagion that many people do not understand that TB is not always infectious. Observing and participating in TB awareness education programmes among Indian communities (Figure 1) made me realise that it was understandably difficult for participants to comprehend the differences between latent and active tuberculosis, and pulmonary and extra-pulmonary tuberculosis. According to one participant:

Ah to people, to Indian people TB means infectious disease. They, they don’t know the difference between non-infectious TB and infectious TB and disease. TB means infectious and that’s what people think (Indian woman in her 30s).

To many Indian people TB means an infectious condition, rather than referring to a specific disease. Three participants told me that some Indians do not differentiate between HIV/AIDS and TB. According to one, “Some people in India don’t see a difference between AIDS and TB” (Indian man in his 40s).

Social stigmas attached to TB among some Asian cultures can prevent individuals from seeking treatment and taking prescribed medication as this reaffirms the individual as having the disease. Delays in seeking and receiving treatment have been found to be common for stigmatised diseases such as TB and leprosy (Predaswat 1992, Rajeswari et al. 2004). Meeta told me she suspected she had TB when she began to lose weight and cough up blood. However, due to the fear of her family finding out she dressed in loose clothing to hide the weight loss and would go to her room whenever she had to cough, so nobody in the household would see the blood.

Blemishes of individual character

Stigma is not solely about fear and (lack of) understanding of disease. For some Indian and Korean people it is attributed to moral conduct and religion. I realised early into the study that for members of these communities a strong association existed between bad hygiene or more
specifically dirt and TB. At this stage I took comments such as ‘TB is caused from dirty carpets’ and ‘unclean people who do not brush their teeth’, at face value. On further investigation I realised dirty also related to spiritually unclean individuals. As Goffman (1963) noted, the process of stigmatisation cannot be separated from the concept of morality. Attributing moral transgression to stigmatised individuals firstly reassures that ‘normals’ remain morally pure and avoid punishment, and secondly helps ‘normals’ to distance themselves from those who are stigmatised and reduce the threat associated with the stigma (Gibbons 1986, Goffman 1963). Goffman (1963:14) classifies this form of stigma as ‘blemishes of individual character’.

Two Christian Korean participants told me that immoral behaviour can result in punishment from God in the form of diseases such as TB and cancer. Four Indian participants also informed me that certain actions such as not fulfilling family obligations, drinking excessive amounts of alcohol and being sexually promiscuous will result in punishment or curses from their God/s or ancestors in the form of diseases such as tuberculosis. A study of TB in India also identified that participants attributed moral causes such as karma and God’s curse to TB (Rajeswari et al. 2004). Further, in a group conversation with several older Indian women I was told that when children do not look after their parents or do not allow them to live with them in their old age the children may be punished by gods with bad health.

Sexual promiscuity was another behaviour attributed to TB. Older Indian people told me that TB was a disease that women got from ‘sleeping around’. Participants from India would often emphasise to me that beliefs such as these are only held by ‘poor, rural’ people. However, I found that these beliefs were maintained by educated, middle-class people from urban areas of India.

Although tuberculosis is a curable disease both my Auckland research and that by Rajeswari et al. (2004) in India found that stigma associated with TB is permanent in nature. I was told by Indian people that when a woman has TB she will always be considered as ‘one of those women’ who are sexually promiscuous. Therefore it is the assumption about the immoral behaviour associated with TB that persists rather than the physical disease itself.

Culturally specific beliefs associated with moral behaviour and TB reinforce notions of stigma and the social isolation of individuals infected by TB through restrictions placed on ‘the diseased’. Indian women with TB are not allowed to have sexual intercourse (or more specifically are to sleep in separate beds from their husbands), are restricted from contact with children and other family members, along with not being able to perform domestic duties such as food preparation.

Indian people believe that when TB is in the home, it is something really bad especially for the women. The stigma is in the home for these people. If mum is having TB she tries not to let children know. TB [is] worse for women because they are main person in family, everybody thinks she should not cook in these areas and mainly, she won’t get [sexual] intercourse. No she won’t get sexual satisfaction and always there is insecurity. And then she won’t be near the children. So if a person has TB, no good. The woman’s whole role really lost (Indian woman in her 40s).

This quote highlights the relationship between stigma and gender. I noticed that different perceived causes of TB often existed for men and women in Indian societies. For men TB was commonly attributed to hard work and stress (although this was not exclusive to men) or drinking alcohol, while promiscuity was only attributed to women.

TB can lead to individuals being rejected or isolated from their families. Social isolation from families can occur in two ways. Firstly the family itself will reject the individual with TB, or
secondly, the tuberculosis sufferer will isolate themselves from their family. Four participants isolated themselves from those closest to them out of fear that they would spread their disease and associated stigma to their loved ones. According to one participant, “The only thing that concerns me is my child, if he gets infected” (Indian man in his 20s). Isolation also has spatial, social, emotional, psychological and physical dimensions as evident from the following quote from an Indian girl in her teens for whom TB influenced her physical interactions with family members:

I didn't know that it was only like, I just assumed that you know, cos I had it that everyone else would [become infected] you know? I was really afraid that somebody else would get it too. I still even still today, it's even though I'm ok, it's still, it's still a sort of thing. Like before I used to you know, give Dad a kiss before I go to bed and you know, like that, but now I kinda don't.

Coping with stigma: Information management

Stigmatised individuals develop strategies for dealing with the devalued status that accompanies their stigma (Becker and Arnold 1986). These strategies are influenced by the degree to which the stigma is shared with others in a society and the degree to which it can be ‘normalised’. Visibility is also important to how well individuals cope with stigma as it is often through visual recognition that stigma becomes evident to observers. Physical symptoms of TB are not as visually obvious as those of other diseases such as leprosy. Therefore an individual’s ‘differentness’ is not immediately apparent to others. According to Goffman (1963:57), in this context individuals manage their stigma and associated relationships with social contacts through information control.

I found that most participants with TB developed a strategy that Goffman terms ‘passing’. Passing involves disguising stigma by controlling and concealing personal information about tuberculosis, therefore denying the disease which would discredit them to others. Seven participants disclosed their TB status only to immediate family although two did tell close friends and employers. Only one participant did not inform anyone of his illness. Along with concealing their TB status three participants went to great lengths to hide their treatment, meeting public health nurses (PHNs) at times when no one else would be in their home or meeting in parks or car parks to avoid work colleagues, friends and neighbours from observing their treatment. I asked participants what they told their friends, family and employers about their absence from work, bad health or time in hospital. Most participants did tell others that they were experiencing health problems but were not specific in details.

One participant told me she followed the advice of her PHN when it came to disclosing her personal information which relieved her anxiety:

Janette my Public Health Nurse she says to me ‘you don’t need to tell everybody that[s] what happened exactly, this is the tuberculosis or anything like that. If somebody asks, just tell them like it’s infection in the spine’. So that’s how, that’s why we don’t tell anybody (Indian woman in her 30s).

Other strategies participants employed to cope with stigma were humour, religion and using western biomedical knowledge to counter cultural understandings of TB. One Indian man in his 20s constantly joked with health care workers, his family, friends and myself about his condition. His use of humour was a coping strategy to deal with his serious health problems and the stigma he faced in his community.
It was more of a thing like ‘Ah you got TB, ah you gonna die’ (laughs) kinda thing. It was like, you just make a joke out of it, after a while it’s like ‘Oh ok, ah don’t worry about it’. It’s like probably the first thing was disbelief like ‘Oh sure whatever’ you know (laughs) ‘Yeah pull the other one’. Yeah and it became a joke, and basically after that um, it’s like they’d take me seriously

Religion was a key influence in the lives of participants particularly in relation to coping with illness. One Muslim Indian man isolated himself from friends and family when he discovered he had TB. Despite this isolation he told me that his belief in God helped and his faith would see him through the illness. When he finally told his wife and parents that he had TB their religious beliefs also acted as a form of support for him “They [his family] said same thing as me, if you believe in God it will be alright”.

Six participants used western biomedical knowledge to counter cultural notions of morality and the contagious nature of tuberculosis. Participants tended to emphasise they were no longer contagious because they were taking medication and the cause of their illness was ‘TB germs’. One Indian man in his 20s told me that he had extrapulmonary tuberculosis and was on medication and therefore could not infect his family or friends; despite my head-nodding and agreement, he insisted I read medical information he had found that supported this assumption. Other participants had collections of TB information pamphlets (from their PHNs) and told me of TB websites and medical reference sources which they had gathered information from.

Even though participants cited biomedical causes for their illness and understood they were no longer infectious to others it was clear they all still experienced social isolation from their community and did not disclose their TB status or biomedical explanations to many people. These are common effects of information control where, “[e]ven if the individual succeeds in concealing the past, a sense of stigma is kept alive by knowledge of cultural beliefs about such behaviour as well as by the need to be secretive” (Becker and Arnold 1986:50).

Support networks

Support networks play a key role in how well individuals manage their stigma. Goffman (1963:31) terms people who support the stigmatised as ‘sympathetic others’ who consider the stigmatised as essentially normal despite their discredited attributes and provide instruction, moral support and comfort. Family members of migrants with TB were key actors for social support, particularly if they lived close by. By way of example, Meeta had migrated to New Zealand after marrying her New Zealand-born Indian husband and lived with her in-laws. Her family encouraged her to seek medical treatment when she was sick and acted as her translators while she was in hospital where they also brought her Indian food and took turns visiting her. Once she returned home from the hospital her sisters-in-law took turns cooking for her and helping with housework. However, not all migrants have such extensive family networks and are often separated from family and friends overseas.

For migrants with limited family networks PHNs became central to their lives in helping them with treatment and support. Goffman (1963:41) describes ‘sympathetic others’ as ‘normals’ whose special situation has made them privy to the secret life of the stigmatised individual and become accepted by them as ‘wise’ persons. PHNs fall under this category; they are aware of the individual’s disease and generally become accepted by individuals with TB. Rather than a purely medical relationship based around treatment, all participants found the support and advice from their PHNs important and helpful in their tuberculosis experiences.
Bhadrak, an Indian man in his 20s, had no family or friends around him when he was hospitalised for three months and his only social contacts were health care professionals. He explained that the PHNs “saved his life” not through their pills but through their care, friendship and support. PHNs were also able to give advice on disclosing health information and helping participants counter social stigma. Participants’ descriptions of PHNs included “best friends”, “helpful”, “caring”, “friendly”, “kind” and “supportive”. It is important to note this aspect of health care provision from PHNs, particularly because of the limited social networks many migrant TB sufferers face.

Conclusion

For Asian migrants stigma operates at many levels - from national discrimination to local group perceptions. Stigma surrounding TB for Indian, Chinese and Korean immigrants in New Zealand is something that is hidden and complex, relating not only to understandings of disease causation and transmission but also strongly linked to social values, moral behaviour and religion. Stigma has significant impacts on tuberculosis creating delays in diagnosis and acting as a barrier to treatment. Stigma is also gendered where different causes and restrictions are seen between men and women. In order for health education to be effective in de-stigmatising TB it must focus on local, cultural perceptions and understandings of TB within specific communities involving men and women from all ages. Health education should also acknowledge and build upon coping strategies used by TB sufferers such as using biomedical information, humour, religion and support networks to help minimise stigma within Asian communities.

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Notes

1 The term ‘Asian’ in this study is applied to the three participating groups. Although there are advantages in using this term there are also many problematic implications. ‘Asian’ lacks specificity, lumping many diverse populations into one homogenous category. However, for many human societies diseases such as TB carry stigma for patients and their families. Research that associates TB with specific groups such as Chinese, Indian or Korean can have essentialist implications and also impede participation of communities due to fear of possible identifiability and public reactions. After consultation with community members, who felt more comfortable with me using the term Asian rather than naming specific communities, I have used ‘Asian’ in this study but at no stage consider it to be an ethnicity.

2 Pseudonyms were used for all participants in the research to maintain confidentiality.

3 I recruited participants with TB through local general practitioners (GPs) and PHNs. GPs and PHNs would ask patients if I could have their contact details and I would then contact and invite them to participate in the research. I was usually notified by health care professionals of new TB cases but would only be given contact information if consent was provided by patients.

4 This observation came from interviews with, and observations of, participants with TB, their family members and health care professionals.
Chapter 17
Health, Wellbeing and Diaspora: The lived Experience(s) of TB in a Refugee Community in Auckland, New Zealand
Jody Lawrence

While many people think of tuberculosis as a disease of the past it continues to be a major health issue, infecting nearly one-third of the world’s population (World Health Organisation 2006). TB is an infectious disease caused by Mycobacterium TB. When healthy people are infected with TB (TBI), 90-95% of people’s bodies are able to control the infection so it remains dormant or latent (Klovdahl et al. 2001). Those with TBI are unable to transmit the infection. The other 5-10% of individuals who become infected later develop active TB disease (TBD). Those with the active disease are infectious and can transmit it through activities whereby bacteria in the respiratory passages are aerosolized and expelled as moisture droplets into the air. Such activities include sneezing, talking, coughing and singing. After the droplets have evaporated, they become ‘droplet nuclei’ which circulate and can subsequently be inhaled by others resulting in infection. The disease usually resides within the respiratory tract (lungs/larynx) however it can occur within other parts of the body (extra-pulmonary TB).

Despite the fact that effective TB medication has been available for over fifty years, in 1993 the WHO declared TB as a global emergency in response to a sharp increase in TB rates in developed nations including New Zealand. Throughout international literature, three factors are commonly cited as the main causes of the ‘new’ TB. These are the emergence of TB/HIV co-infection, an increase in multi drug resistant TB (MDR TB), and immigration. While there have been a number of researchers who have considered the influence of immigration on TB epidemiology, few have explored what it is about the process of immigration and being a migrant that is resulting in high TB rates. Even fewer have endeavoured to consider these issues from the perspective of those with TB. This chapter reports on three themes that have emerged from my PhD research undertaken with Somali refugees living with TB in Auckland, New Zealand. Drawing on interview narratives, I explore the way in which Somali refugees’ migration journeys have impacted on their experience of resettlement and subsequent experience of TB. Participants spoke about the multiple losses in their lives. Firstly, the losses resulting from the eruption of civil war and the ensuing refugee experience. Many Somalis struggle with all-encompassing grief that hinders their ability to resettle in New Zealand. These challenges directly contribute to a second loss faced by participants which is the diagnosis of TB. Despite improvements in treatment and knowledge about the disease, TB remains highly stigmatised and feared amongst the Somali community. In many ways, TB further isolates and disadvantages those who are already marginalised. In addition, a number of individuals face a sense of ongoing loss in terms of their health and wellbeing. Although all individuals I interviewed successfully completed and complied with their TB treatment, a number continue to experience ongoing health issues relating to the damage to their bodies caused by TB. This finding has particular significance for countries such as New Zealand, where health professionals promote TB medicine as the means to “cure” TB. This however is not necessarily the case as participants’ accounts will demonstrate.
TB & Immigration

One of the dominant explanations of the resurgence in TB is the increased movement of people from high TB incidence areas to low incidence countries. While these migrants comprise only a small percentage of the total population, they are responsible for a significant proportion of the TB burden. For instance, immigrants constitute 60% of TB notifications in New Zealand (Ministry of Health 2003a), 64% in Canada (Health Canada 2000) and 79% in Australia (Gilroy and National TB Advisory Group 1999). In many cases TB rates amongst those born overseas are 10 to 20 times greater than for the host population (Littleton et al. 2008). For instance, in New Zealand the TB rates per 100,000 were: Pakeha 1.5, Maori 12.3, Pacific Islands 34.9, and “other ethnicities” 74.4 (Ministry of Health 2003b).

Focusing upon the Somali population in Denmark, Lillebaek et al. (2002) posit that the doubling in TB cases over the last 15 years is largely attributable to the arrival of Somali immigrants. Between 1991 and 1999, 57.5% of reported TB cases were foreign-born, of whom 37.8% were Somali. In Minnesota, Kempainen et al. (2001) found that although Somalis account for less than 0.4% of the Minnesota’s population they comprise 17% of TB cases and 23% of all foreign-born cases. The researchers found 82 cases of TB amongst the Somali population between 1993 and 1998 resulting in an incidence rate of 170 per 100,000.

Given the association between immigrants and TB, one of the main public health responses is to screen migrants for a wide range of diseases and health problems either prior to, or shortly after arrival. Yet there is research that challenges the assumption that screening upon arrival will necessarily identify and resolve infectious disease and thus provide the degree of protection desired. In New Zealand only 20% of foreign-born TB notifications occur within the first year of arrival in NZ (Ministry of Health 2003a). Nearly one-third of notifications occurred after five years of residing in New Zealand, thus suggesting that active TB is not merely imported. Although Farah et al. (2005) found that TB rates in Norway were the highest in the first two years following migration, rates remained much higher amongst immigrants than the Norwegian-born population even seven years post-migration. In Canada, Cowie and Sharpe (1998) established that the mean period between arrival in Canada and diagnosis of TB was 11.2 years with a median of seven years. The interval between arrival and diagnosis depended on the type of TB contracted with pulmonary TB having the longest interval and TB in the lymph node the shortest. The authors state that, “The risk of TB for immigrants is the same as prevails in their countries of origin, but there may be little general awareness among physicians that foreign-born residents remain at significant risk for many years after their arrival in Canada” (Cowie and Sharpe 1998:601).

One of the reasons why public health authorities screen immigrants upon arrival is to protect the host population from disease and infection. However there is evidence that challenges this assumption by suggesting that transmission of TB from immigrants to the host population is very rare (DeRiemer et al. 1998, Heath et al. 1998, Chin et al. 1998). Using DNA fingerprinting, Lillebaek et al. (2001) found very little transmission of TB occurs between migrant and host populations. Of the 391 Somali patients in Denmark with culture-positive TB between 1996 and 1998, three-quarters were reactivations of old TB infections with unique DNA sequences. The remaining 23.3% were likely to have been infected by other Somali immigrants. Only 1.8% of Somalis were likely to be infected by Danes. The authors speculate that the limited social contact of Somalis with the host population makes it unlikely for immigrant-host transmission to occur.

One particularly interesting finding in the study conducted by Lillebaek et al. was that TB rates amongst Somalis living in Denmark may in fact be the same or higher than TB rates in
Somalia (Lillebaek et al. 2002:682). While this finding is not universally supported (Watkins et al. 2002), it does raise interesting questions about whether the social, economic and political environment in which migrants are living is facilitating the development of TB. While the comparison of TB rates between countries is problematic due to differences in detection and data collection, it shifts the focus from the ‘diseased migrant’ to the quality of living conditions in the host country.

Elender et al. (1998) discuss how although ethnic minorities tend to experience much higher rates of TB than the host population, the recent increase in TB in England and Wales does not correspond with the increase in immigration from high-incidence countries. They describe the debate over whether ethnicity or poverty is the main determinant of TB and cite studies that found TB rates amongst the white population and immigrants from the Indian subcontinent were very similar in deprived areas (Cundall and Pearson 1988, Goldman 1994). The authors critique other studies which tend to assume that the variable of ‘ethnicity’ can be easily compared with other variables such as ‘overcrowding’ or ‘unemployment’. They state that, “[w]ithin such groupings (ethnicity) are a wide variety of genetic backgrounds, cultures, lifestyles and health-related behaviours, any of which may contribute to tuberculosis levels” (Elender et al. 1998:679). Furthermore, the label ‘ethnicity’ masks the high degree of variation between ‘ethnic’ populations.

Antunes and Waldman (2001) support the idea that rising TB rates cannot solely be explained by immigration from high incidence areas, but that the multiple needs and deprivation of immigrants increase the risk of transmission and reactivation of TB. Kistemann et al. (2002) used statistical analysis to consider risk factors for TB in Cologne, Germany. They found that although there was a strong positive association between TB incidence and immigration, there was evidence for a correlation between TB incidence and deprivation indicators, particularly between ethnicity and economic indicators. They conclude by suggesting that it may be wider deprivation that is associated with higher rates of TB rather than immigration. In a similar vein Kempainen et al. (2001) suggest that the large TB burden in the Somali population in Minnesota is due to multiple factors such as poverty, overcrowding and limited medical resources.

While immigration has been repeatedly linked with the re-emergence of TB many researchers have engaged with it in a limited, almost binary way. Many studies are limited to discussing whether or not immigration has caused the resurgence in TB, whether TB is imported or not and the length of time between arrival and notification. While these questions are important, they fail to adequately explain what it is about the process of immigration and being a migrant that is resulting in high TB rates. While there is a wealth of literature on the health impacts of being a migrant (e.g., Jatrana et al. 2005, Ingleby 2005), this avenue of investigation has not been well-explored in respect to TB.

Furthermore, many of the studies on immigration only focus on one significant migratory journey - from ‘there’ to ‘here’, when in fact mobility is an ongoing process in the lives of migrants. The broad implications of this mobility are not well understood in relation to TB (c.f., Warfa et al. 2006 who consider the connection between mobility and mental health), a disease for which long-term care and relationships with health-providers are required.

Although immigrants clearly have far higher rates of TB than local populations, many studies have failed to disentangle the different types and characteristics of immigration flows. One could argue that there is a vast difference in circumstances, and thus health status, between an immigrant who moves to another country to take up a professional position and a refugee. In addition, the process of classifying people as ‘immigrants’ and ‘foreign born’ versus the ‘host
population’ when discussing TB rates is a somewhat artificial duality given that many migrant families have children born in the country of resettlement.

One of the main shortcomings of the literature on the effect of immigration on TB rates is that many commentators fail to engage with the lifeworlds and realities of migrants in order to understand why migrants experience high TB rates. While we know that immigrants have high TB levels, there are few studies that seek to understand what it is about being a migrant that leads to TB. Littleton et al. (2008) suggest that focusing on the experiences of migrants can help explain why reactivation occurs. Such factors include the nature of the migratory journey itself and the process of resettlement in which migrants may face discrimination, language barriers, lack of social support, difficulty obtaining employment and limited financial resources. This can damage health and wellbeing, and lower immunological resistance, thus rendering migrants vulnerable to health problems including TB (Jones and Moon 1987).

The Auckland Somali community

Before considering the different losses associated with TB, it is important to survey the events that lead to the arrival of Somali refugees in New Zealand. Somalia came to the world’s attention in 1992 with the circulation of ghastly images of famine and violence from the protracted civil war. After many years of conflict and tension, civil war broke out in 1988 resulting in widespread displacement, hardship and loss of life. The situation became even more desperate with the onset of famine in 1991 which, combined with the effects of the civil war, resulted in the loss of life of between 240,000 – 280,000 Somalis. In 1992, nearly 75% of children under five died from malnutrition as famine became widespread (Kalipeni and Oppong 1998). By the end of 1992, nearly 500,000 people were living in 13 refugee camps in Kenya. Since that time nearly one million Somalis have sought refuge in other countries (De Montclos 2003). Despite the efforts of the United Nations and other international organisations to broker peace deals, Somalia has no national government due to the persistence of conflict and violence.

This provides the backdrop to the arrival of the first Somalis in New Zealand in 1993 as part of the United Nations High Commission for Refugees (UNHCR) quota (New Zealand accepts 750 UNHCR-mandated refugees annually). Quota refugees were resettled in main centres, particularly Auckland but also Wellington, Christchurch and Hamilton. According to the 2001 Census there were 1770 Somalis living in New Zealand (Statistics New Zealand 2001), although this figure is likely to be much higher due to census under-counting. Somalis appear to have mixed resettlement experiences, with many experiencing difficulties in terms of education, employment, housing and health (Madjar and Humpage 2000, Lilley 2004, Jenkinson 1999, Guerin and Guerin 2002, Denholm and Jama 1996). These challenges have had a profound influence on the health and wellbeing of Somali refugees and have contributed to the subsequent development of TB amongst this population.

Methods

In order to consider the experience of TB amongst Somali refugees living in Auckland, I undertook community participation, participant observation and interviews between March 2003 and December 2005. In total, I interviewed 25 individuals with TB disease or infection and their families. These individuals were recruited with the assistance of public health nurses. Interviews and focus groups with general Somali community members were also
carried out. I also interacted with scores more through extensive participant observation and community participation.

It took a great deal of time and effort to establish the trust and credibility necessary to discuss sensitive issues surrounding health, wellbeing and personal journeys. Recruiting participants for TB interviews proved to be highly problematic with many individuals refusing to participate. This was in part due to the continuing stigma attached to the disease and the level of suspicion about me and what I was doing. Interviews were however a rich and rewarding opportunity to learn about the issues individuals face and the way in which they make sense of their world. They also offered me the chance to spend time in people’s homes and catch a glimpse of the texture of everyday life.

I was also fortunate to participate in community life in a number of different settings and in a number of different roles ranging from researcher through to evaluator, report-writer, videographer and friend. I was able to share in important community events such as weddings, soccer matches and consultation meetings and also in the mundane realities of everyday life such as errands, cooking and childcare. Becoming involved in the community was not a simple task and was at times a tumultuous process of self-doubt and despair. Yet just as equally, it was a rewarding time as people welcomed me into their homes and their lives.

Themes

The experience of loss: forced migration and resettlement

Many of the individuals whom I interviewed spoke of an overwhelming sense of loss and displacement. While this can clearly be linked back to events surrounding the civil war, this sense of loss was broad and all-encompassing and profoundly influenced everyday life. Individuals spoke about the loss of family and friends, personal health and wellbeing, their national identity and pride, history and memories, material resources and assets, social resources, social status and educational and employment status. Many participants felt as though they had ‘lost themselves’ and everything that they used to hold dear. This sense of loss is aptly described by one participant:

I had to leave. We had to leave all the cars and the houses, everything. We had to take nothing, even no food, nothing. Just walk. When we came to Kenya, you know, the refugee camp, my husband died there. So life was getting really hard. Coming to NZ was good, but I thought you know I don’t belong in NZ. I feel you know, my heart is in my country. Because in my country I had big home and big family. Lucky. But NZ, no big family, no big house (Participant F).

The loss and displacement that was experienced prior to coming to New Zealand was also compounded by challenges experienced during the process of resettlement. Not only were participants living with and reliving the trauma of what had happened pre-migration, but were also experiencing considerable distress and difficulty during the resettlement process. These challenges include difficulties with finances, employment and education, language, contracted social networks, dealing with separation and finally, but quite importantly, problems related to being a ‘visible other’ and frequent target of negative attention at both the neighbourhood and political level.

Of the Somalis interviewed as part of this research, many described how they arrived in Auckland with high hopes for a better life but soon became disappointed as resettlement challenges mounted. This sense of disappointment was keenly felt and many participants
described their lives here in New Zealand negatively compared to their lives back in Somalia. One of the greatest resettlement challenges relates to finances. Nearly all participants receive government income support. While Somalis were grateful for the provision of such assistance, it has proved difficult for many to pay for day-to-day living costs particularly when you are starting again from scratch. One of the contributing factors to the socio-economic hardship experienced by Somali refugees is difficulty obtaining employment. Although there is a lack of comprehensive data, research conducted by Fisk (2003) suggests that up to 85% of refugees are unemployed. Of those I interviewed, despite some holding professional qualifications and having considerable employment experience as teachers, nurses, doctors and scientists, very few individuals had been able to obtain employment. According to community leaders, these high rates of unemployment are due to a variety of factors including Somalis lack of English, transferable skills and also discrimination and reticence on the part of New Zealand employers to employ Somali refugees.

Closely linked to challenges related to income and employment are issues of education and language. As discussed, while a number of Somalis have tertiary qualifications many of these are not recognised in New Zealand. This reinforces a sense of vulnerability and isolation from the wider structures and opportunities of New Zealand society. As a result, those individuals have lost the status they once enjoyed in their homeland. It also presents challenges in terms of finding a job. Some have undertaken retraining but this, in conjunction with English language learning, represents a significant investment in terms of time and finances. As a result, many of these individuals are currently unemployed or are unable to find employment that reflects their qualifications and experience. There have however been a small handful of individuals who have undertaken English language and subsequent tertiary education. Only a small proportion has gained employment upon graduating from such programmes and many struggle to find a job alongside the many other New Zealand-born applicants.

Another important resettlement issue is that of housing. Housing provides not only material shelter but also a sense of security and protection. For refugees who arrive in New Zealand as part of the annual quota, Housing New Zealand undertakes to settle refugee families in state housing and places them at the top of the very long waiting list. However, it is not easy to find suitable homes for refugees. Much of New Zealand’s state housing stock was created in an era where the notion of the nuclear family reigned supreme. For those refugees who were fortunate enough to be resettled into a Housing New Zealand home, other problems were encountered. Many participants complained that their homes were cold and damp and that this contributed to poor health, particularly amongst children. Requests to Housing New Zealand for carpeting had been declined. One participant had raw sewage leaching through her garden and experienced considerable difficulty trying to address the situation with Housing New Zealand. In the end, she requested the assistance of the public health nurse who was treating her for TB to write to Housing New Zealand to try and get a transfer.

Due to the shortage of state houses and the long waiting lists, if tenants move out of their house they are not automatically entitled to another state house but re-join the waiting list. This is of particular relevance to Somali refugees who are highly mobile. Their mobility has proven to be difficult for a number of families who have been involuntarily settled in other cities in New Zealand but have relocated to Auckland for additional family support. They find themselves in a situation of not being entitled to a state house and required to find accommodation within the private rental sector. This is not a straightforward undertaking and a number reported difficulties finding a home let alone affording high market rents. A number of Somalis stated that they experienced discrimination based on their skin colour and nationality.
The Auckland Somali population is highly concentrated in the Mt Roskill area. Mt Roskill is a highly diverse suburb that is home to people from many different nations. While these groups live in close spatial proximity to one another the social distance between them is vast. Not only are many Somalis struggling with a lack of social support but also that of physical isolation. Given that much of the Auckland region is designed with vehicles in mind, those without cars are significantly limited in their ability to venture outside their home. This is a primary reason why so many Somalis wish to live in the Mt Roskill area to be close to other Somalis who have clustered there.

Within the New Zealand context, official recognition and provision for the needs of refugees and migrants is limited after arrival. Political and media debates about the ‘place’ of refugees in New Zealand has also contributed to a sense of vulnerability and hostility towards ‘others’. At the local-level, political ambiguities towards refugees and migrants have been manifested in a real and visible way. Somalis have exerted considerable agency in their efforts to support one another during the harrowing resettlement process. One important dimension of the community is the establishment of pan-clan organisation, the Auckland Somali Community Association founded in 1996 to assist Somalis with resettlement and represent Somalis to government and NGOs. The ASCA has a quasi-governmental organisational structure with different community members holding portfolios based on their skills and experience. Since becoming an incorporated society, the ASCA has become a significant service-provider and has established a number of initiatives including a swimming programme for women, youth holiday programme, small business training, parenting programmes and health promotion programmes to name but a few.

Within the present research participants cited a variety of problems such as one family who found that their neighbour dumped rubbish on their property, name-calling and Somali school students being teased about being refugees. As a result, many participants reported that they tended to socialise solely with fellow Somalis and limit their interaction with other nationalities. Although the Somali community can be differentiated along the lines of gender, socio-economic status and clan groupings, it is a close-knit community with strong networks and structures in place. This has occurred in part due to the separation of families and the desire to maintain a strong Somali culture and identity within New Zealand.

What is interesting is the way in which a number of participants directly linked these hardships to the subsequent development of TB. When I asked about the cause of her TB one participant stated,

Sometimes I’m thinking too much, for example I had the TB. So I believe that TB attack me because I was thinking too much. I was worrying about my family back home a lot. Sometimes I go to the toilet and I just sitting on the toilet but I was thinking of my family. I have got a big family and I can’t afford to fix their problems and I can’t afford to send whatever they want so I was thinking, thinking, thinking a lot (Participant H).

Essentially many Somalis experience multiple and overlapping layers of disadvantage, factors which have been linked to the prevalence of TB. One example in this case is overcrowding within the home. One family of nine whom I worked closely with currently lives in a small 2 ½ bedroom home. Because of this, when one family member developed TB, six other family members became infected. While there are a number of reasons for this overcrowding, including socio-economic and cultural factors as well as a lack of public housing stock in Auckland, it has direct implications in terms of the development and spread of TB.

Not only do these factors contribute to TB specifically but to poor overall health and wellbeing. Particularly prevalent amongst the participants I have worked with are very high
levels of stress and worry which compromise the ability of the immune system to contain the TB germ upon infection. While there is weighty evidence that suggests that immigrants have high rates of TB, the short vignettes given above indicate that the post-migration experiences of migrants directly influence health and the likelihood of developing TB.

**Yet another loss: being diagnosed with TB**

Given the profound challenges faced by Somali refugees as described above, the diagnosis of TB was constructed as yet another example of loss - loss of health, wellbeing and the ability to live the kind of life they hoped for. Many discussed the impact the diagnosis of TB has had upon their lives. While academics and health professionals devote considerable resources to ensuring individuals with TB become non-infectious as soon as possible, the social ramifications of TB are experienced well past the point of infectivity. Within TB literature, stigma is used as an explanation for particular behaviour such as delayed presentation at health facilities or non-adherence to treatment regimens. Yet surprisingly, there are few accounts that seek to understand the meaning and experience of stigma for individuals with TB as a topic of enquiry in its own right. While reducing the risk of transmitting the infection to others is of utmost concern, it is important not to minimise and overlook the experiences of individuals with the disease.

TB continues to be a stigmatised disease and this made it very difficult to conduct research on the topic at times. A number of individuals with TB who were approached by public health nurses to participate in this study refused because they were frightened of what might happen if they did so despite reassurances of confidentiality and anonymity.

Stigma is a complex phenomenon and is not uniformly experienced. When discussing stigma, two contradictory narratives emerged about the seriousness of the condition. Some participants were eager to assure me that TB is ‘just like the flu’, a disease of the past and that Somalis are now well educated about the illness and are no longer fearful of it. This is what I term the ‘public’ account of TB. Privately however, participants acknowledged that they had experienced discrimination and been stigmatised due to having the disease. Individuals’ strenuous efforts to limit disclosure about their illness and conceal the true nature of their sickness are testament to this. In the words of one individual who tried to hide her diagnosis from others:

Jody: How do you think people would react if you did tell them?
A: They will run away from me.
Jody: Really?
A: Yeah. They will be like, you know, think they get disease or something, it can infect them.

When asked about the impact of TB on their own lives, participants frequently spoke about isolation and separation. This isolation occurs both physically and socially throughout the various stages in the TB journey (diagnosis, treatment and post-treatment). For those with pulmonary TB, isolation occurred in a physical sense after being diagnosed with TB and subsequently hospitalised. This isolation within the ‘Infectious Diseases’ ward at the hospital is designed to confine the spread of the disease and is the first of many instances of isolation that follow. This enforced isolation was a particularly difficult time for many participants as they were particularly unwell and also coming to terms with the social ramifications of their illness. For some, the face mask was symbolic of the social harm caused by TB and was a tangible and visible manifestation of stigma. When hospitalised with pulmonary TB, a face
mask usually had to be worn by patients and visitors. This requirement appeared to be strictly enforced by hospital staff.

A number of individuals reported a greater sense of social isolation and contracted social networks post-diagnosis once their TB status become known to the community. As the Somali community is small and extremely closely-knit, it was very difficult for participants to keep their illness secret. A common phrase that was used to describe the reaction of fellow community members was that “people will run away from me”, reinforcing a sense of isolation and exclusion. Other participants spoke of how friends now actively avoided them and would no longer visit and, if they did visit, would not eat with them. Another said that while she still received visitors, they say bad things about her behind her back. Interestingly, those who were the most marginalised (socially, physically and economically) before contracting TB tend to be those who experienced stigma the most. This is well-demonstrated in an excerpt of dialogue between me and one participant about issues to do with stigma and isolation.

Jody Who have you told about your TB?
S I haven’t told anyone – no-one asked. But people found out. It’s a small community.
Jody And did those people act differently towards you?
S Yes of course. They don’t want to be close.
Jody And what about other friends?
S I don’t have contact with anyone. I don’t have any friends.
Jody Is this after you had TB?
S Before and after

Part of this sense of stigma and shame seems to be linked in with the way that TB was perceived as being incurable and equated with certain death. One community representative likened it to AIDS, while another participant stated “I thought I was dead, gone and going to hell” when she found out she had TB.

Ongoing loss: the long road to wellness

The final theme that emerged somewhat unexpectedly was the ongoing loss participants faced after completing TB treatment. Despite successfully completing the harrowing treatment process, a number of participants continue to suffer from the effects of TB on their body and face a long road to wellness. While stigma is frequently cited as a reason why people avoid seeking medical attention, for my participants this did not appear to be the case. Many of the individuals I spoke to had visited their general practitioner up to twenty times before being correctly diagnosed. In most cases there was a very long time gap between the development of first symptoms and treatment – in many cases this was between nine and twelve months. This was in part due to the type of TB participants were presenting with such as extra-pulmonary TB which manifested itself in places such as the back, lymph nodes or stomach. This made diagnosis difficult and by this stage most participants were extremely unwell, requiring lengthy periods of hospitalisation at which time the diagnosis would be made, once all other options had been ruled out.

Turning our attention towards the treatment phase of the timeframe, the dominant issue within academic literature and for health practitioners alike is that of compliance. Successful completion of the treatment course (i.e., compliance) is posited as the only means of achieving a cure for TB and enormous resources are devoted to ensuring this occurs. Yet in
the group of people that I have worked with, because they became so sick before being diagnosed, they continue to live with the effects that TB has had on their body even though they are no longer infectious, have complied and completed the required course of treatment. The end of treatment is a significant milestone for the participant and health practitioner alike, yet there was a sense that once this stage had been completed and the individual discharged from the care of public health workers, participants now faced the task of managing the long-term health effects that TB had on their body. One individual who had extra-pulmonary TB was confined to a wheelchair for three months and required home help for two years.

Another participant who had pulmonary TB continues to experience coughing, throat pain, vomiting, dizziness and lack of appetite. Despite completing her treatment she is in a similar place as she was prior to diagnosis with concerns about her health. This is a frustrating situation with Participant I expressing great fear that the TB may return. In her words:

> Until now I coughing you know now. I see the doctor in Greenlane hospital every three month and I went to the doctor and I said “You should check me again because I cough too much, even now I cough and I vomit” and they say “No now it’s ok”… I was taking the medicine one year. I said “You need to check me again because I still cough too much” and they told me “No, you are ok” and every three months I go to see doctor and they say “No you ok, you don’t have anything, maybe it’s, you know the … damage in your body [due to TB] and that's why (Participant I).

Although she has no clear idea as to why she is still feeling unwell, her health is very marginal as the following account demonstrates:

Jody  So even now, you can't eat much

I  No. Even people they eat three times a day, I eat one time, only lunch

Jody  And how much would you have

I  Small. Little

Jody  So do you feel strong, does your body feel strong

I  No

Jody  No

I  And even sometimes when I, I stand you know, I feel….

Jody  Dizzy?

I  Yeah.

At a chest clinic appointment I attended with her, the specialist stated that due to the extensive damage to her lungs, she would continue to experience problems on a long-term basis.

Conclusion

While migrants are frequently blamed for the ‘TB problem’ in developed nations, little is known about the mechanisms that are contributing to the high burden of TB amongst this group. This paper has sought to contribute to debate on the significance of immigration to TB rates by highlighting the way in which the experience of TB must be adequately situated within the everyday lives and contexts of those with the illness. Drawing upon the findings of thesis research conducted with Somali refugees living in Auckland, I discuss three themes related to the notion of ‘loss’ in order to add to our understanding of the reasons why groups such as Somali refugees experience a high burden of TB. In order to do this I have endeavoured to document the everyday lives and lifeworlds of Somalis prefaced by an
understanding of their migration histories. Participants spoke about the multiple losses they had experienced in their lives and the way in which these losses had had a detrimental impact on their wellbeing and ability to resettle in New Zealand. Some participants directly linked these losses to the subsequent development of TB.

The diagnosis of TB was yet another loss for participants and another obstacle to be overcome. Participants spoke about the ramifications TB has had upon their health and social standing in part due to the enduring stigma attached to the disease. Despite suggestions that stigma has improved due to increased education about the disease, most individuals went to great lengths to hide their illness and experienced considerable isolation when the truth emerged. The final theme highlights the extent to which TB can result in ongoing loss with many participants facing ongoing health issues related to their experience of TB. Due to the length of time before diagnosis, many individuals were extremely unwell and continue to live with the after-effects of the damage the disease has had upon their bodies.

While this paper has only briefly touched upon three aspects of the TB journeys faced by Somalis, I have attempted to highlight why it is vital to consider the lived experiences of migrants/refugees in order to understand the burden of TB amongst this group. TB is not experienced in isolation from wider life experiences and struggles, a point which was directly acknowledged by a number of my research participants. For many people I spoke with, TB is associated with profound loss with many ramifications for the lives and wellbeing of those concerned.

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References


Chapter 18
Placing the Experience of Pacific Peoples Living with Tuberculosis in Auckland, New Zealand
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This chapter poses the problem, derived from the perplexing statistics outlined below, of what it is about the lived experience of Pacific peoples in Auckland that helps us to understand why these communities have continuing relatively high rates of tuberculosis. New Zealand, like other developed nations, has recently experienced a resurgence in TB since its low plateau in the 1980s (Crump et al. 2001). The national incidence rate has plateaued again in recent years at 10-11 per 100,000 (Das et al. 2006a).

TB has long been associated with migrants in Western nations and this association is also found in New Zealand (King 2003). However, incidence rates vary widely between ethnic and migrant categories. Currently, people who are migrants or recognise descent from migrants from Pacific islands have four times the rate of TB compared to the New Zealand average and have the second highest rate of the four ‘ethnic groups’: Pakeha, Maori, Pacific peoples and ‘Other’ (Ministry of Health, 2004). Das and his group’s recent work on New Zealand age-standardised incidence rates by ethnicity show that the rate for Pacific peoples is 22.3 times higher than the European rate (Das et al. 2006a). The category ‘Pacific peoples’ includes both migrants and New Zealand-born residents and citizens and, because Pacific people travel frequently between the islands and New Zealand, none of these categories is particularly stable. However, it is not possible to explain Pacific TB in New Zealand by recourse simply to a high TB incidence in most Pacific nations. With the exception of Tuvalu, the rates in the other Pacific island nations which are most commonly represented in New Zealand (Samoa, Cook Islands, Tonga, Niue, Tokelau, and Fiji), are no higher and in many cases considerably lower than they are in New Zealand.1 The strains of TB transmitted among Pacific people in New Zealand are usually fully responsive to treatment and not associated with HIV (Voss et al. 2006). The preventable and treatable nature of this TB therefore raises the question as to why these rates continue at such a high level.

After sketching in a brief background to Pacific peoples in New Zealand and Auckland we outline the ethnographic study that was conducted by the lead author and present themes from this research that address our problem (see Figure 1 for a location map). Following the thinking of social geographers like Eyles (1985) and Kearns (1993), a key concern in the study was place – both in the literal sense of the where of everyday life as well as the sense of social status and identity conferred upon those with TB (i.e., ‘place-in-the-world’). Our concern in this paper is less the particularities of the places occupied by participants (residentially or otherwise) and more their placement in the context of urban Auckland while (in most cases) maintaining connections to the Pacific home-place.

Nationally, Pacific people comprise six to seven percent of the population, but approximately 15% of the Auckland population. Mass migration to New Zealand began post World War 2 during New Zealand’s economic boom. To a large extent, Pacific people were initially integrated into the unskilled and semi-skilled working classes, subject to the economic instabilities and withdrawal of welfare that New Zealand experienced in the latter quarter of the 20th century. Particularly over the last decade, a minority have experienced educational and career success to the point that there is now a small but significant middle class (Anae et al. 2000). Despite these trends, Pacific peoples’ average earnings, educational achievement
and home ownership rates are lower than the national average (Anae et al. 2000). Since the 1980s Pacific population growth has been domestically driven as indicated by the 2001 census that reported 58% of Pacific peoples as being New Zealand-born (Statistics New Zealand 2004). However, some groups, for example Tuvaluans, have experienced particular circumstances on their home island and specific responses from New Zealand in terms of immigration and labour policy which have led to more recent migration to New Zealand (Chambers and Chambers 2001). The identity implications for New Zealand-born Pacific peoples and differences between the life experiences of the island-born and the New Zealand-born lead to differences in health beliefs, health-seeking behaviour and the use of traditional medicine. Nonetheless, there are frequent interactions of people, goods, information and money between New Zealand and the home islands.

Study Design
The researcher who conducted the fieldwork for this study, Roannie Ng Shiu, is a New Zealand-born Samoan. There is a strong emphasis in this chapter on the experiences of Samoans because Ng Shiu was able to use her established connections in order to facilitate focus groups, especially when English was a second language for some of the participants. While we recognise that there are differences between Pacific cultures and between the migration experiences and residency status of different groups, in this short chapter it is not possible to adequately deal with this diversity. Instead we focus on the commonalities of migration experiences and shared cultural understandings. The study used mostly qualitative methods and involved semi-structured interviews with Pacific TB patients, focus groups with
Pacific community members and informal discussions with health professionals. It took place in 2005 and formed the basis for Ng Shiu’s (2006) Master of Arts thesis in Geography.

With the assistance of the public health nurses (PHNs) in Auckland, all TB patients in the Auckland region who identified themselves as being of Pacific descent were invited to participate in the study. Through this process a total of 11 participants were interviewed. Four of these people had begun treatment in 2004, when there were 53 TB cases involving people of Pacific island descent. The other seven had commenced treatment in 2005, when 18 TB cases occurred in people of Pacific descent (see Figure 2 for number of cases). The participants identified themselves as being of Samoan (6), Tongan (1), Cook Island (2) and Tuvaluan (2) descent. The participants’ ages ranged from three years to 77 years with an approximately even mix of males and females. Only two of the TB patients interviewed were born in New Zealand. Most had migrated to New Zealand well over 10 years earlier, with two participants having lived in New Zealand for almost 40 years and the most recent migrant arriving in 2000. All interviews were conducted at the participants’ residences which was their choice.

![Figure 2](image-url)  

**Figure 2** Number of TB cases by Pacific ethnicity 1995-2005. Prepared by R. Ng Shiu, based on data supplied by Dr C. Thornley, ARPHS

Although the interview questions were open-ended, in some cases it was quite difficult to establish free flowing dialogue and as a result some of the interviews were quite brief. The difficulty in trying to engage some participants in in-depth narratives may have been due in part to their migration status and their being uncomfortable in talking about their health condition.

Two focus groups were conducted with Samoan community members who were not TB patients nor related to any TB patients. The main aim of these focus groups was to try and gather understandings of health and TB in the community at large. The first focus group comprised five men and three women between the ages of 40 and 52. It was conducted in
both English and Samoan. The second focus group comprised four young people: two men and two women, all of Samoan descent and between the ages of 19 and 20.

Informal discussions with health professionals also took place. These included discussions with Pacific doctors during a peer group meeting on tuberculosis and diabetes for Pacific general practitioners (GPs) around diagnosing and treating Pacific patients. Also, Ng Shiu had informal discussions on directly observed therapy with some of the PHNs treating Pacific TB patients.

All the interviews and the focus groups were recorded and transcribed verbatim and then analysed thematically. The themes which shed most light on the experiences of Pacific peoples’ TB in New Zealand and gave clues as to why TB continues at its relatively high rate are the relationships between Pacific and Western medicine, health culture and explanations of the causes of TB, perceived differences in the type of TB experienced in the islands and in New Zealand, and social networks and living situations. These themes are discussed in turn.

**Western medicine and traditional medicine**

Despite living in New Zealand and the availability of many western medicine health providers, many Pacific peoples, including those born in New Zealand, opt to use traditional healers. In this study only three out of the 11 participants had not seen a traditional healer whilst eight participants reported visiting traditional healers on a regular basis. Three participants opted for a traditional healer when they first became ill with TB, without knowing it was TB at the time. The use of traditional healers is intensified by structural limitations in accessing western health care and providers. One participant who went to see a traditional healer first before seeking out a GP through relatives, indicated that he had problems with accessing a GP on his own:

> I went to a healer and the healer said I better go to the doctor. I didn’t want to because it was hard. So my uncle had to come with me and help see a doctor at the (medical centre). A healer is easier to see, you just go there and see them, you don’t have to do anything else. I only went once to see a healer, he lives in Otahuhu. There were heaps of people at the healer. (Tongan man in his 30s)

The eight participants who saw traditional healers on a regular basis also had western doctors whom they saw as well. The participants mostly attended Pacific health providers where the doctors and staff understood Pacific languages, contexts and living situations. This situation is illustrated in the narrative below:

Interviewer: “…So the first time you ever saw a GP was when you came to New Zealand?”

Participant: “Yeah. But then we don’t like that one…”

Interviewer: “…so this is when you went to see (Tuvaluan doctor)…so did you guys go and see him just because he’s Tuvaluan?”

Participant: “…Yeah that’s the main thing we look for, some of the Tuvaluan people can’t speak English (pause) or understand the English language, for them they go to see him.” (Tuvaluan man in his 50s)

Medical pluralism is common for Pacific peoples as they move frequently between Pacific and western health frameworks. This movement was evident in the study as a few of the participants used both western medicine and traditional healers in treatment for TB. For example, a three year old Tuvaluan TB patient was suffering from terrible side effects from
the antibiotic medication given. The elements of traditional healing such as massaging, traditionally used to help soothe body pains, became an important component in the treatment of TB by this young boy’s mother. The dialogue below is illustrative:

Interviewer: “Are you still seeing traditional healers now?”
Participant: “Yeah.”
Interviewer: “and what is that for?”
Participant: “umm just you know they (soothe) the body.” (Mother of a three year old Tuvaluan TB patient)

Macpherson and Macpherson (1990) argue that the Samoan medical framework does not dismiss western medicine but, rather, Samoans like to adapt that which works for them from the western health framework. Thus, the choice of health framework is often dependent on the success of treatment for the ailment. The following quotes illustrate this contention.

My belief is that I’ll take the medicine that makes me better, whether it be Samoan medicine or medicine from the doctor. (Samoan female TB patient in her 50s)

Well, being a Samoan and all, ah, I don’t see anything drastically bad about Samoan medicine and that…I feel that, you know, healing is a God-given thing and ah, you know, God can work and can perform those types of medicines too. (Samoan male TB patient in his 50s)

Generally the participants believed that both Western and Pacific models of health were legitimate and did not view one as being superior to the other. Most of the participants living in New Zealand had a dual health framework in which they moved easily between the two systems, utilising the framework which best fulfilled their needs. However, some of the New Zealand-born Samoan participants had a different view of traditional medicine that was informed partly through their upbringing in New Zealand. They saw Western medicine as superior because of technological advancements and the rigorous training at prestigious Western institutions, whilst traditional medicine was seen as ‘backward’. The following quotes illustrate this view.

Oh I think that like the English medicine is a whole lot better than the Samoan ones…when it comes to the medical stuff I just like the experts. (Samoan female TB patient in her 20s)

…they (traditional healers) learnt their medicine from you know outside in the backyard from their parents. It’s not like their real job, it’s just something they grew up with. (Samoan female focus group participant in her teens)

The above responses concerning Western medicine and traditional medicine demonstrate a level of acculturation. These young New Zealand-born Pacific people view traditional paradigms through western cultural perspectives of health, biomedicine and science.

Visiting a traditional healer was not related to delayed diagnosis for this group of participants, but, as described above, one of them went in the first instance to a Pacific healer because he was not confident enough to visit a GP by himself. This healer referred him to his doctor, but it was only when members of his family network assisted him that he attended the GP and was diagnosed. This suggests that perceptions about the accessibility of western doctors and the structural reasons which create such barriers to access can play a role in diagnostic and, hence, treatment delays for TB. Further, cooperative and complementary relationships between Pacific and western health care workers, as in this case, can have a role in facilitating early diagnosis and treatment.
Health cultures and explanations of TB

The initial reaction from participants when they were finally diagnosed with TB varied significantly depending on commonly held constructions of TB in the past, and whether or not the participants had had any previous experiences with TB. The concept of health culture is used to refer to ‘understanding and information people have from family, friends and neighbours as to the nature of a health problem, its cause and its implications’ (van der Oest 2005:3). Health cultures derive from experiences over time and in a particular cultural context. For many of the younger participants, finding out that they had TB was not a big issue as they had limited knowledge or understanding of what TB was. To them it was just another illness like bronchitis. However, for some of the other older participants finding out that they had TB came as a horrible shock and surprise. The wife of one TB patient suggested she would rather her husband be afflicted with cancer than TB. The following quote illustrates her strongly stigmatised view of TB:

So (he said) they said to me they said that they hope that I got TB. Why, why because I was thinking when I was in Samoa…it was a what you call a very contagious TB and people are living on their own in the other place and no one allowed to go…But when I went there (hospital) I was shocked and then he said to me that the doctor told me that it’s better if I have TB because its curable…and I said ‘Oh I never knew that there was medicine for cure for TB’. (Samoan woman in her 70s).

Three participants had experienced delayed diagnosis. One participant had been misdiagnosed with a severe cold by their family doctor in Auckland for up to one year before the correct diagnosis of TB. The other two participants had delayed seeking medical help due to their own attempts to self-diagnose. Although those participants who delayed seeking medical help said that they would have sought help had they realised they had a serious disease like TB, the tendency to self-diagnose and to act on this self-diagnosis for long periods of time may also be related to the fear of loss of reputation. In two instances in this study, delays in seeking medical attention led to the spread of TB disease and infection among family members in several households, including children. In one instance, the delay in seeking attention was compounded by delay in receiving a diagnosis of TB.

For many Pacific peoples, illness is inherently the result of social causes (Kinloch 1985, Baddeley 1985, Parsons 1985, Macpherson and Macpherson 1990). Serious illnesses were considered a consequence of either the patient or a family member having done something wrong in terms of cultural protocol and conduct or as a result of straining a relationship with another, whether another person, ancestor or God (Drozdow-St Christian 2002, Macpherson and Macpherson 1990). Thus, the cause of TB in the past for many Pacific peoples, in Tonga and Samoa especially, was not seen as solely or even primarily biological but rather due to social factors. TB was classified as a serious illness because of the lasting visible physiological damage that TB has on a person (Ah Ching et al. 2001). Pacific people may therefore try to hide the fact that they are ill in order to avoid accusations and suspicion being cast on their family. As a consequence, Western medical clinics may become a haven because of the secrecy and privacy of treatment.

The seriousness with which TB was viewed meant that the TB patient and/or a family member must have seriously contravened a social custom or relationship with another being (Drozdow-St Christian 2002). This can partially explain the stigmatisation and isolation of TB. Therefore TB patients may be kept in isolation in order to save the family’s dignity and reputation from any suspicion of wrong-doing.
…when you had TB in Samoa in those days, you’re isolated. You, you, you’re kept in a room on your own, everything is done is separately from you and all that…well, [you had a] special cup on your own, and your, and your dish, and your spoon, and your knife [was separate], no. I hate those kind of things  (Samoan female TB patient in her 60s).

The quote above illustrates the purposes of isolation. It was a means of distancing the person from the family, trying to limit the damage done to the family’s reputation, and a mechanism to prevent the spread of the disease. During the 19th and early 20th centuries, TB was an important cause of death in the Pacific (McArthur 1967). There was no reliable cure and as such TB was often associated with death. This therefore led to a great fear of TB as a fatal disease.

For Samoans the fear of the social effects of diagnosis was further intensified by TB control procedures practiced by the US Navy in American Samoa. From 1921 to 1960, the US Naval Medical Department began an aggressive TB control campaign where non-cooperative and contagious patients were forced into isolation by the legal system. Those in isolation had few visitation rights and therefore had little to no contact with family and friends (Ah Ching et al. 2001).

Although the campaign was eventually stopped the legacy and memories still live on through folklore and storytelling. This makes attempts to destigmatise the disease in Samoa difficult at present. Another challenge in trying to eliminate the stigma associated with TB is re-educating Pacific communities about the treatments and cure for TB. Many older Pacific peoples do not realise that there are now effective treatments for TB, as the following narrative highlights:

Participant: “You know, TB is like the same as [leprosy].”

Interviewer: “Really? Why would you see TB the same as [leprosy] when the symptoms are different?”

Participant: “Because they’re both fatal; they have no cure.” (Samoan male focus group participant in his 50s).

In the past, leprosy was also considered a seriousness illness in Samoa as its treatment, as for TB, was isolation. However, leprosy was an even more extreme case, with sufferers often being exiled to an offshore island leper colony. Today, the association of leprosy and TB is still evident in Samoa. At the National Hospital of Samoa in Moto’otua, the leprosy and tuberculosis services are housed together in a small clinic at the end of the hospital campus. The picture below (Figure 3) is of the TB/Leprosy Clinic signage above the clinic’s door.

![Figure 3](TB_Leprosy_Clinic_Signage_Apia_Samoa.jpg)

**Figure 3**  TB/Leprosy Clinic Signage, Apia, Samoa. Photography: R. Ng Shiu
Duality of TB

Many of the older Pacific participants believe that there is a duality to TB in which there is a Samoan TB and a New Zealand TB, and that the latter is not as bad as the former. This perception stems from their past beliefs and their recent experience of TB in New Zealand. Their experience of TB in New Zealand has been more positive as treatment for the disease is readily available and the disease, once identified, is curable. Patients are constantly being reassured by doctors that the disease is the direct result of biological factors. A biomedical explanation is invariably regarded as better than the alternative social explanation. If biomedical reasoning for illness is plausible, Pacific patients will tend to stress that it can be nothing else but biomedical. The following narratives exemplify this notion,

Nobody knows, except my family…But they [the doctors] said that it isn’t like the TB that we used to have that was very contagious and very bad (Samoan female TB patient in her 60s).

I was taken to the hospital and they did blood tests and things like that then it was known that I was [afflicted] with the TB germ (Samoan female TB patient in her 50s).

…that’s how they [the doctors] said some, that TB germs can live, can be within a person for all his life and not knowing until something happens and it triggered that to come to the front of things, that brings it to, that comes out to be TB so I just go along with it, information from the doctors and their instructions (Samoan female TB patient in her 60s).

For the elderly Samoan participants interviewed, their past experience of TB was ominous, especially their experience of unsuccessful treatment and fear of those with TB. For these people it was thought that, once you had TB, certain death was near. This was one reason why the wife of one participant had real concerns about her husband coming home from hospital after isolation. Once Paul had been cleared of being infectious he was released to go home. However, the process was not that simple because his wife was absolutely opposed to him coming home. It took three doctors from Auckland Hospital, as well as her GP, to convince her that her husband was no longer infectious and that it was safe for him to return home.

Drozdow-St Christian (2002) argues that, for Samoans, the dignity and honour of the family is paramount, and safeguarding and protecting the family’s reputation from any social disrepute can sometimes supersede treatment as a priority. This premise may help to understand some Pacific people’s behaviour in terms of dealing and coping with TB. For example, the denial of a participant’s mother over her daughter’s illness with TB can be explained as the result of fear surrounding the social repercussions of having TB, as the following dialogue indicates:

Participant: “Yeah, ah, my island side there, they were like going, kept telling me to go down and see my grandmother and that. And that it’s not TB, it’s just, um, it’s something just, lumpy. She [my mother] didn’t believe that it was TB.”

Interviewer: “Aha, and what did you tell her?”

Participant: “I kept telling her it’s TB and she didn’t believe me when I kept, I showed her like this… ‘cause I got a scar and that. I showed her my medication and she didn’t believe me.” (Samoan female TB patient in her 20s).

Later, when asked why her mother did not think it was TB, the participant said she did not know. Her mother never told her why she thought it was not TB but insisted that it just could not be the disease. This puts into perspective what another participant commented on about Samoan attitudes toward TB and the ‘not in my backyard’ syndrome which sees TB as a disease of the ‘other’:

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I, I feel sorry for them (TB patients) but at the same time I’m glad it’s happen to them and not in my family (Samoan female focus group participant in her 30s).

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

Social networks and living situations

A social network connects an individual with social contacts such as kin, neighbours and friends. Social networks are beneficial for those who have to adjust or cope with a major change in life, such as migrating or when faced with a serious health issue (Stansfeld 1999). Social networks can also be detrimental to health as they can facilitate the outbreak of infectious disease (Klovdahl et al. 2001). This is of major concern to Pacific peoples as they have many social networks that are not necessarily spatially concentrated. Internal migration plays a significant part in the spread of TB infection and outbreaks, and Pacific people move quite frequently within New Zealand (Ministry of Health 2004). They often visit other family members across New Zealand for lengthy periods of time, especially when they first migrate to New Zealand, to find the best location and employment opportunities that suit their needs (Macpherson 2004). The transmission of TB then becomes more complex as its geographical distribution can widen with the movement of a single individual. For example, one Cook Island participant, Tara, had stayed with family in Wellington where, according to contact tracing, she initially caught TB. She then moved to Auckland, unaware that she was infectious. The household that she moved into in Auckland then increased to 10 individuals with four adults and six children living in a three bedroom home, due to relatives visiting from the islands. Tara’s household composition reflects a common plight for many Pacific peoples with important implications for health, as previous studies examining health and welfare implications of housing and lack of income have indicated (Milne and Kearns 1999, Cheer et al. 2002).

Another case of overcrowding from this study involved the Tuvaluan participants, with five adults and five children living in a three bedroom house. One adult and one child were being treated for TB disease and three other children were being treated for TB infection at the time of this study. This particular family’s extended family lived at another address in a suburb nearby. The circumstances of this second household also led to the spread of the disease within it. What has proven to be a challenge for the Auckland Regional Public Health Service in terms of contact tracing is that members of both households frequently move between the two addresses so that it is difficult to know who exactly lives where. Although this poses a problem for the public health service and especially for the nurses administering DOTS, these arrangements are only natural for this Tuvaluan family. The household as it is known in New Zealand is different to that in the Pacific. It is not confined to a single dwelling. The term ‘home’ for many Pacific peoples could be a number of households in which any close family member resides.

Crowding has been shown in the international literature to have an adverse effect on health and is associated with higher rates of infectious diseases in general, and tuberculosis in particular (Gray 2001:20-21). Although crowding is just one of a constellation of factors to
be considered in the ecology of TB, being frequently associated with poverty and food insecurity, it is an important one: a 1998 study by Elender et al. estimated that “for each 1 percent increase in the numbers living in crowded accommodation (defined as over one person per room) the average notification rate increases by 12 percent” (cited in Gray 2001:21).

The particular difficulties described in these case studies of TB in Cook Islands and Tuvaluan familial networks are not isolated accounts. Reports of outbreaks over several years in Pacific communities in New Zealand (e.g., Voss et al. 2006 who describe a paediatric outbreak), demonstrate high “attack” rates (i.e., many people infected from the source case), difficulties in diagnosis, treatment and contact tracing, and the spread of disease from adults to children. Mobility of people within New Zealand and between households was implicated in the paediatric outbreak, and the authors point to the difficult social and economic conditions and immigration status of many of the families involved. All of these factors are apparent in the families in our study.

Apart from the family, the other two most important social networks that participants used were their friends and their church. For many Pacific peoples, interaction with church contacts occurs frequently, especially when people become involved with church groups and committees such as Sunday school, mothers’ group and choir. Many of the participants indicated they were involved in many groups and sub-committees in the church that had weekly meetings. Interaction during the week can also be increased, especially when there are events or festivals that the church is taking part in such as choir competitions. Furthermore, for recent migrants social networks become a vital and integral source of comfort and knowledge in terms of navigating and accessing the New Zealand health system. This was evident when the Tongan participant had difficulty in registering with a local GP but with the help of his uncle he was finally able to register at his local primary healthcare centre.

The Tuvaluan community is still relatively small and those who were first to become established in Auckland became important community liaisons for new migrants. The Tuvaluan participants in this study were often accompanied to appointments at the hospital by a community member who acted as the interpreter. Such community members are important especially for new migrant patients who become overwhelmed and stressed when having to deal with multiple health specialists all at different locations.

The most common theme that pervaded participants’ narratives is that those who emphasised the seriousness of TB did not tell their friends or church members that they had the disease. This was despite their friends often being aware that they had health problems. When asked if anyone apart from their family and friends knew that they had TB, some of the participants responded in the negative:

I don’t tell them [friends] that I had TB um, they know that I have a community nurse that comes around. But they always ask questions, they go “Oh, is there anything wrong with you?” and I go, ‘Oh don’t worry about it, it’s something that can be cured,’ and they go “ah, sweet.” Yeah, ‘cause it’s embarrassing for me and I know I should tell them (Cook Island woman in her 30s).

As previously mentioned, TB for many participants has always been associated with marginalisation and death. It is not surprising, therefore, that members of this group were somewhat guardied in sharing knowledge of their illness. Some participants had been reassured by the doctors that TB is no longer the disease they feared in the past, but, despite this reassurance, some participants still refrained from informing friends about their situation, with obvious implications for the ability of their social networks to support them.
There were a few participants who had no qualms about sharing knowledge of their illness with others outside of their family. One elderly Cook Island participant had many friends who were part of her congregation and who also knew that she had TB. She explained that before becoming ill with TB neither she nor her family had heard of the disease, nor could think of how she contracted it. Thus, because they viewed it as akin to pneumonia which she also suffered, TB was seen as just like any other illness that can be treated. What was comforting for Mere was that her friends often visited and held prayer meetings which comforted her and left her in high spirits. This illustrates Stansfeld's (1999) argument that quality support from social networks can facilitate well being. It is unfortunate that few of the other participants were able to share this experience.

There are some cases where the disclosure of a patient’s TB condition is unavoidable. For instance, one participant had been ill for such a long period that over time it became common knowledge amongst his social networks that he had a serious health problem. As with most Pacific families, when a family member becomes ill it becomes a family affair (Kinloch 1985, Laing and Mitaera 1994, Tukuitonga 1990) and so family members try to be helpful and look into finding the right treatment. Thus, a larger group of people can become involved in seeking health advice as one participant illustrates:

…you know, Samoan family, so I mean we’re tight and all that. In a way, when someone’s as ill as I am, you know, everybody’s concerned (Samoan male TB patient in his 50s).

Family concerns for this participant meant that, once he was diagnosed, a large group of people found out that he had TB. However, the participant expressed that he would have preferred for knowledge of his illness to be kept within the family:

Oh yeah, yeah, the whole community (knows)…if I had a choice too I wouldn’t let anyone know, but it’s just that, in my case, people had known that I’d been ill, so can’t really help that one (Samoan male TB patient in his 50s).

For all the participants in this study, families were their main source of comfort. They provided much needed emotional support through the often lengthy and difficult treatment process.

The living situations for many Pacific families in Auckland are not as optimistic and promising as many Pacific migrants had envisioned. Pacific peoples are over-represented at the lower end of the socio-economic spectrum (Ministry of Health 2004). The median income for Pacific peoples in 2002 was $14,800 compared to $18,500 for the rest of the nation (Statistics New Zealand 2004). Furthermore, the unemployment rate for Pacific peoples is twice that for Europeans. Despite the fact that most Pacific families moved in order to seek a better future for their families, the current living standards and situations of Pacific peoples indicate that their expectations of a better future have yet to be realized (Macpherson et al. 2000:78)

The impact in change of lifestyle and change in ‘place’ often results in new challenges and stresses that migrant families have never faced before. Therefore, trying to cope with these challenges becomes increasingly difficult, especially when there are multiple demands on families for money for living expenses, remittances, schooling and so forth. One participant, a young New Zealand-born Samoan, believed that his illness was a result of the stresses that he was under at the time, indicating that emotional stress was a key factor that led to the onset of TB disease. At the time, he had been living away from home in a hostel and was having issues at work. Consequently, Luke found himself caught up in a bad situation with substance abuse, as his story illustrates:
Interviewer: “Do you have any idea of how you got it [TB] then?”
Participant: “I don’t know if it had come through ‘cause of stress and stuff.”
Interviewer: “Yeah…”
Participant: “It does, yeah that was probably a big factor then…cause I wasn’t living at home.”
Interviewer: “And that was stressing you out?”
Participant: “Yeah, work and where I was living”
Interviewer: “All that stuff, oh I see.
Participant: “And a mix of something else!” (Samoan male TB patient in his 30s).

This participant’s perspective on the causation of his illness illustrates the holistic nature of the Pacific paradigm of health as well as demonstrating the important link between Pacific peoples’ health and well being and family.

Conclusion

Pacific peoples’ experience of tuberculosis in Auckland is informed by a combination of traditional beliefs and western biomedical perceptions and practices which reflect the places of significance in their lives and which are negotiated in a context of changing health and immigration realities. There are invariably inter-generational differences as well as differences between Pacific-born and New Zealand-born people in terms of health beliefs and health-seeking behaviour, as well as differences between the various Pacific cultural groups. Pacific peoples continue to seek traditional healers and, for some of the participants in this study, traditional healers are their first point of contact for healthcare. This is in part a result of preference but in one instance in our study, and perhaps of wider significance, it was the result of a structural failure in rendering western healthcare accessible for Pacific migrants. Difficulty in accessing and consequently using primary healthcare services is an impediment to the timely diagnosis of TB. Many of the older Pacific participants have very stigmatised and negative views of TB associated with their health culture. However, people may revise their views if the successful treatment of ‘Pacific’ TB in Auckland was more widely known within the community, indicating positive health outcomes in relation to TB for Pacific peoples. The significance of sharing this information with older Pacific people and recent migrants must not be underestimated as a positive intervention in eliminating the stigma of TB. This, in turn, can lead to people utilising their social networks more effectively to help cope with the illness and facilitate well being. This is especially important in relation to TB where the course of treatment is lengthy.

As discussed earlier in the paper, the places of residence (dwellings and neighbourhoods) for Pacific peoples in Auckland frequently reflect the influence of poverty and its effects (e.g., household crowding). This situation reflects the structural position of Pacific peoples in New Zealand and the associated vulnerability that arguably renders them more prone to TB than other usually resident population groups. As Cheer et al. (2002) indicated, the complex interplay of factors such as housing and income can lead to the ‘discounting’ of health-enhancing activities, such as going to the doctor and the purchasing of healthy food. The data that Das et al. (2006b) recently reported showed a TB incidence rate in Pacific children under 10 years old that was the highest of all groups in New Zealand and twice as high as that of ‘Others’. This finding may well speak to some of the consequences of the ‘discounting’ of well-being brought on by impoverished conditions in everyday life. The perspectives presented in this paper add a human face to the urgency of this data and speak to the need to look upstream from indicators of illness to the determinants of health experience.
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References


Notes

1 Rates in many Pacific nations with small populations are difficult to calculate and need to be interpreted with caution, particularly those where a population of a few thousand has, for example, one case and/or there are difficulties of enumeration both in the population and for cases. The most recent WHO (2007:254) incidence figures for 2005 for those nations who have contributed most to the New Zealand population are Samoa: 20, Tonga: 25, Cook Islands: 16, Niue: 44 (one case), Tokelau: 56 (one case), Fiji: 23, Tuvalu: 305. These compare with a Pacific Islands-born incidence rate in New Zealand of 48.7 and a New Zealand-born Pacific peoples’ incidence rate of 23.2 for the years 2000-2004 (Das et al. 2006b: Table 2). All incidence rates are per 100,000.

2 Our study took place at the ‘tail end’ of a long running outbreak in the Pacific population which began in 2002. In 2003 the incidence rate was at its historic high of 95.3 (Voss et al. 2006:118).
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