



Talking about TB: multicultural diversity and tuberculosis services in Waikato, New Zealand

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Abstract

Aim To explore the diversity of opinion amongst different refugee and minority group representatives about tuberculosis, and to examine the provision of services and their effectiveness in the Waikato Health District, New Zealand.

Methods Open-ended qualitative interviews with the representatives of seven minority populations were undertaken. The interviews focused on the cultural differences in the approach of minority populations to health issues and on the accessibility of health services to these population groups. Participants expressed their opinions about how health services, and more specifically about how tuberculosis (TB) health services could be improved.

Results Important cultural differences between the minority populations were elucidated by community representatives that may determine the interpretation of symptoms and timing of presentation at medical services, the appropriate cultural processes to be followed in the consultation, and adherence to prescribed treatment.

Conclusions The absence of health services oriented towards specific minority and refugee groups, and communication difficulties with healthcare providers, are important cultural barriers to TB control in Waikato. Recognition of the diversity of these populations, and the cultural and structural barriers that they face in accessing health services in Waikato and other similar health districts in New Zealand, is needed. The development of strategies is required to reduce barriers to TB treatment so that patients from diverse cultural backgrounds can be diagnosed early and effectively treated.

New Zealand has one of the lowest rates of tuberculosis (TB) in the world, but has high rates in the indigenous Maori and non-European immigrant populations.¹⁻⁶ TB is an infectious disease that is prevalent in developing countries.⁷ It is transmitted through airborne droplets or through the ingestion of infected food, and results in disease of the lung and (less frequently) other body organs.⁷

In New Zealand and other developed countries, increasing immigration from high TB incidence countries and the deterioration of control programs as a consequence of reduced Public Health funding have resulted in an increased incidence of TB.^{2,8-11}

A recent study examined the effects of the changing socioeconomic, cultural, and geographic characteristics of TB cases in the Waikato Health District (WHD) of New Zealand from 1992 to 2001.¹² That study documented the persisting high incidence of TB amongst Maori, as well as the significant rise in the incidence of TB amongst migrants from countries with a high prevalence of TB. Therefore, it is important to examine the accessibility and delivery of health services to the Maori and immigrant populations.

In August 2002, the *Waikato Refugee and New Migrant Strategic Plan – 2002 to 2007* was released.¹³ This document is designed to address the broad areas of social integration, health, education, literacy, and employment of new immigrants in the WHD. The authors describe the plan as a response ‘to the challenges of resettlement and meeting the often complex needs of these new (immigrants) and their families’.¹³

The plan is also described as ‘the first significant attempt to plan and fund inter-sectoral service development for refugees and new migrants within the Waikato region’.¹³ Within the area of health, the plan recognises significant problems amongst refugees and new migrants (such as issues of access to healthcare services, non-compliance with treatment, inability to meet the cost of medicines, and failure to keep appointments) and subsequently makes several recommendations.

Our study is designed to achieve a better understanding of both the cultural differences between different minority populations in their understanding and approach to TB health issues, as well as to better understand the various barriers that these different populations experience in accessing health services.

With the development of this knowledge, health services (including those for the management of TB) can more effectively meet the needs of these populations and fulfil the aims of the *Strategic Plan*.

Methods

The research was undertaken over a 3-month period from January 2002 to March 2002. It was decided that community representatives (acting as proxy respondents for their community group) would be approached to participate in this study. Reasons and the potential biases for this decision are presented in the discussion section of this paper.

Participants were selected by using the contact list in the *New Settlers Handbook*, which lists all immigrant communities and the contact details of community representatives. From the largest community groups, seven individuals were contacted and given information about this project, and asked whether they were available to participate. Arrangements for the interviews’ location and time were also arranged. Representatives from the seven minority populations agreed to participate and were subsequently sent a letter outlining the purpose of the research project (see Table 1).¹⁴

Each interview was undertaken in English at a venue of the community representative’s choice. Open-ended questions were used to elicit each representative’s opinions about the significance of TB for their community; these included the community’s perceptions of the current level of TB services, and the community representative’s thoughts about how these services could be improved.

At each interview, the responses to each of the questions were recorded in note form by the interviewer, and then transcribed following the completion of the interview. Whilst many researchers tape-record (and later transcribe) interviews for later analysis, we did not have the funds or resources to carry this out. However we were able to make detailed notes during and after each interview which resulted in very little loss of detailed data.

We were unable to show each participant these notes and allow them to change any incorrect emphases, after the completion of the interviews, due to the lack of funding for return visits to give the appropriate level of time and personal contact necessary to allow for feedback. This may have affected the results received, however the researcher was able to clarify statements and provide feedback to participants during the in-depth interview and later by phone.

The Waikato Ethics Committee and the Northern Territory University Human Research Ethics Committee approved this study.

Table 1. Minority populations included in the research project at Waikato Health District, 2002

Minority population from	Population size
Kampuchea (Cambodia)	762
China	4752
Cook Islands	4353
Maori	64185
Philippines	543
Samoa	3141
Somalia	492

Source: Statistics New Zealand.

Results

TB beliefs—Whilst all respondents reported that TB was well understood by their communities, several community representatives stated that the symptoms of TB (a persistent cough) were often not recognised or misattributed to other conditions. For example, the Maori representative articulated that lung cancer was often attributed to the symptoms of TB.

There were a variety of other reasons noted by community representatives to explain why TB may not be recognised. Asian representatives reported a widely held belief that TB is not prevalent in New Zealand, thus individuals were less likely to recognise symptoms. Other respondents, such as the Kampuchean community representative, described particular sociocultural beliefs, such as the transmission of TB only occurs within particular family groups and leaves other families immune.

Other groups were aware that overcrowded housing was a problem associated with TB. For example, the Phillipino representative suggested that *Doctors could help improve the treatment of people by helping to reduce the overcrowding that often occurs with these families, when two families may decide to occupy one house.*

Several community representatives discussed the stigma associated with TB, which affected their understanding of the disease. For example, migrants who had recently arrived from countries with high levels of TB and the older generation of the Pacific Island and Maori population (who could remember when the incidence of TB was high in New Zealand) were reported to hold high levels of stigma. However, the concept of stigma was not uniform across the different community representatives.

Stigma was often interpreted as a fear of getting a disease that was believed to be incurable and highly contagious. In other cases, stigma was described as resulting in isolation of the affected individuals until treatment has been completed. The Kampuchean representative reports that *the family will react to an individual who has been diagnosed with TB by isolating him in different degrees because of the significant fear that TB engenders for most Kampucheans.*

Somali, Asian, and Maori community representatives reported that stigma had been reduced with very simple health education stressing that TB is curable.

Barriers to access to healthcare services—Several barriers to accessing healthcare services were identified by the community representatives. These varied from issues

around the high cost of accessing primary healthcare services to a preference for alternative forms of treatment. Community representatives also discussed reduced access to health services and relatively high levels of unemployment among their minority populations.

Difficulty in accessing primary health services, such as local general practitioners, was reported by the representatives from all groups as one of the main reasons that healthcare is deferred.

All the representatives reported high levels of unemployment in their populations, and consequently the consultation fee charged for each visit to the primary healthcare service is not affordable for them. For example the:

- Somali representative said that (as 95% of the Somali community are beneficiaries) many are simply too poor to attend the GP, and thus will tend to present in the later stages of any illness (including TB).
- Cook Island representative said that there are several reasons for not going to a doctor, with perhaps the most important reason being their inability to afford the cost of going to see a doctor, and there being no 'free' health services in Hamilton.
- Kampuchean representative said that unaffordable or irregular transport services further restrict access to primary healthcare services.
- Maori representative said that nurses need to recognise that patients do not have the transport to be able to pick up their medication.

Various community representatives (such as the Chinese, Maori, and Pacific Islanders) reported that individuals may not access healthcare from a medical service because they choose instead to use traditional healers. However, this was not the case for all communities with the Somali representative describing that many recently immigrated Somalis who had experienced high TB-related morbidity and mortality rates in their native country preferred to seek medical attention from a health service at an early stage of onset, rather than from traditional healers.

Service provision in the healthcare setting—In the provision of health services, community representatives were asked further about the difficulties their community members experienced within the healthcare setting. Responses ranged from articulating who should speak, who should be included in the consultation, and the importance of following cultural protocols.

All community representatives noted that important cultural differences exist between the different populations in the preferred styles of health consultations. In the Somali and Asian populations, community representatives described that communication with the patient is normally undertaken through the head of the family. Whilst this is normally a senior male, the family matriarch undertakes this role in the Cook Island community.

Each community representative emphasised that consultative care involves the entire family, though assuming different formats. Nevertheless, there was a concern that involving the whole family may affect the degree to which a patient may disclose health information in the health setting.

All community representatives reported that individuals often feel unable to identify with a health professional who is not from their own cultural background, and are uncomfortable in the health centre setting generally.

Concerns about confidentiality result in individuals not fully divulging their health problem and limiting the consultation's usefulness. Specific cultural protocols are often not understood or followed by the health centre.

The Samoan representative described that *individuals need to be consulted and seen in a familiar environment by nurses, healthcare workers and social workers who are of their ethnic background and speak their language, in conjunction with the public health nurse or physician who is treating them.*

The Maori representative also stressed the importance for continuity of care with the need for Maori nurses. Such nurses, the representative stated, are better able to establish a relationship of trust and communication by knowing different members of the family of the particular individual, and also in being *able to use the symbols of the Maori culture to help increase someone's knowledge about this disease.*

Amongst the Pacific Islander groups, there was a perceived need for an ethno-specific health services, with the Cook Islander representative stating *a Cook Island primary healthcare service is a very high priority but this aspiration is currently being stifled by very inadequate available funding.*

Communication barriers in the health consultation were reported by the representatives of all the communities. The Samoan representative describes that immigrants who are fluent in conversational English also experience communication difficulties because they do not understand the medical terminology used by medical staff.

The Pacific Island representatives identified that communication difficulties may result in misunderstandings and confusion and are a primary contributing factor to non-adherence. A lack of language-appropriate written information on common health issues (including TB) and prescription instructions were also identified by the Chinese, Somali, Kampuchean, Phillipino, and Cook Island representatives. Each immigrant community representative advocated the need for interpreters, with the proviso (for issues of disclosure) that interpreters need to be acceptable to the family.

When discussing service provision, the issue of adherence to treatment was also raised. Communities who were reported as having a high level of knowledge concerning TB (either through direct experience either in the past or from their home country) reported high levels of adherence to treatment.

Other community representatives (especially the Phillipino, Chinese, and Kampuchean) said that their community members generally believed in the efficacy of prescribed medication. The Kampuchean representative describes that *people in (her) community are very happy to (take medications), and are generally very diligent about taking and completing courses of medication prescribed to them. This appears to be a reflection of the fear and anxiety that they hold about TB, coupled with the vivid recollection of the people who died from TB in refugee camps, and in Kampuchea'.*

In this case, historical memory of TB from an immigrant's home country can result in individuals seeking and complying to mainstream TB treatment. However, adherence to TB treatment and prescribed medication more generally, was reported by the Pacific Island and Maori representatives to be poor in their communities. They reported that reduced adherence to medication can often be the result of ambivalence about the merits of prescribed medication over traditional medications, by the adverse side effects of TB medication, or as a result of insufficient or misinterpreted medical advice.

The Maori community representative described that medication can also be easily lost or misplaced in large mobile family households. In addition the lack of transport creates difficulties in accessing medication from pharmacies. Both the Pacific Island and Maori community representatives reported that treatment is often discontinued prior to completion once the symptoms are resolved.

Discussion

This project explored the commonalities and differences between the issues faced by different minority community groups around TB and the provision of services in the Waikato. Demographic changes (with the increased number of refugees with TB) make this research timely for TB services in Waikato and for other predominantly rural districts of New Zealand.

The study results reveal key themes around the signification of TB beliefs, access problems, the need for cultural sensitivity via culturally appropriate communication, and cultural practices and issues related to adherence.

In approaching the health needs of these populations, it is important to recognise both the social and cultural diversity, and the various barriers they face in accessing health services.¹⁶⁻¹⁸ Without this recognition and further research, the development of health services will be ineffective—leading to poor treatment outcomes, the failure to improve the health of the patient, and failure to eradicate TB as a public health problem in the Waikato district.¹⁶⁻¹⁷

In talking about TB with community representatives who spoke as proxy respondents for their communities, this study does not claim to be representative of the attitude of entire community groups, however it does suggest some key themes and issues that require further and more systematic investigation.

The use of data from proxy respondents has been well canvassed in the literature and is often used in research that requires health information to be collected by direct interview methods.¹⁵ Where there are limited resources for collecting large numbers of interviews, or where the index respondents are unable to be interviewed due to sickness or cognitive impairment, the use of proxy respondent has been particularly useful.

More recently, proxy respondents have been used as a means to identify key issues for further investigation. However, the use of proxy respondents is not without its pitfalls. For example, Nelson et al argued that the item response rate is affected by the topic of the question, the degree of details required, and the relationship of the index and proxy respondent to each other.¹⁵

Further problems include over-reporting, under-reporting, and misclassification of responses due to the specific characteristics of study questions. Despite these issues, this study opted for the proxy respondent approach for several reasons.

Specifically, the research represents an investigative scoping approach, where preliminary attitudes and beliefs around TB were sought to inform future research. The Waikato Ethics Board did not permit interviews to be carried out with individuals who were affected by TB unless trained translators were present. The funds of this project could not cover these costs so it was decided to select community representatives who had a high level of English skills.

We recognise that these individuals are not representative of all members of their community and that they may well have had their own intentions and motivations in agreeing to be part of this study. However the researchers felt that given the circumstances, it was important to continue with the interviews and that community representatives would be able to provide important and culturally relevant information.

An important finding from the interviews conducted in this study was that TB has a particular cultural context for different ethnic community groups, related (in part) to their recent past experience of the disease. Rubel et al, describe these cultural contexts succinctly as the 'health culture' of the patient, which they define as 'the understanding and information people have from family, friends, and neighbours as to the nature of a health problem, its cause, and its implications'.¹⁶

Other recent research indicate that understanding the particular cultural background of a patient gives useful insight into health decision-making behaviour and subsequently the degree of adherence to prescribed treatment.^{17-18,19-20}

Cultural differences are also reflected in the different cultural practices for health consultations, including the different roles that the family plays in these. This is an important issue for health services in both identifying appropriate cultural practices and accommodating family consultations. Family involvement in consultations also raises important issues (including the confidentiality of disclosure between the patient and health professional, and the appropriate care of the individual who may be experiencing TB related stigma).

Interviews with community representatives suggest that stigma related to TB is an important factor associated with non-completion of treatment. Stigma related to fear of contracting an incurable disease, and of being isolated from family, was described as affecting an individual's response to developing symptoms and the timing of their presentation at health services.^{16-17,19,21-24}

With appropriate education, community representatives also noted that stigma was reduced through improved education about health issues, an observation with clear and important implications for health service planning.

In developing effective health services for immigrant and indigenous populations in a multicultural society such as New Zealand, it is important to recognise that poor health outcomes (associated with populations) have often been erroneously attributed to cultural factors alone.^{22,25-26} However structural barriers such as class, gender, and age have been shown to impact on the delivery of health services to marginalised populations, such as those documented here, in previous research.^{21,25-26}

There is a well-documented relationship between migrants, low socioeconomic status, and poor health outcomes.²⁶⁻²⁹ TB is an interesting and appropriate case study for this due to the link between poverty, TB, ethnicity, and the associated issues such as stigma in this life-threatening disease.

In this study, interviews with the community representatives may indicate that (in comparison with the general New Zealand population) minority groups in the Waikato experience reduced access to health services and inadequate housing. Education levels were not mentioned by any of the community representatives in this study and it is difficult to ascertain whether this is relevant without further research. However, lack of the financial means to pay for services, combined with associated transportation costs, were found to be significant in explaining low attendance to health services.

In addition to barriers in accessing health services, interviews with the community representatives also suggested communication barriers by minority populations when utilising existing healthcare services. Subsequently, the net result of health consultations were described as being confusing, involving misunderstandings, and resulting in low treatment adherence. Communication difficulties are also reflected in an earlier New Zealand study, including a study of refugees in Porirua (Wellington region) which concluded that the major unsatisfied health need for this group of refugees was interpreting services.³¹

Health services in the WHD incorporate both ethno-specific and mainstreamed health services. *Ethno specific health services* have been developed outside of the confines of the established health system for minority populations. *Mainstreaming services*, on the other hand, are health services to minority populations that are delivered within the established health system.

Julian, in outlining the arguments for both forms, describes that 'basing service delivery on ethnicity tends to segregate and marginalise migrants, but ignoring ethnicity and catering for migrants only within general services can mean neglecting special needs and perpetuating structural discrimination'.³²

The last decade has seen the development of some ethno-specific primary healthcare services for Maori. However the majority of minority populations do not have easy access to ethno-specific primary healthcare services. Interviews with community representatives, particularly amongst the Pacific Island communities, declared the need for their own ethno-specific primary healthcare services and community health based organisations. In explaining why Pacific Island community representatives were more forceful in their attitudes (concerning a need for such services) may be related to the overall longer length of time that such communities have been established within the broader society.

The development of such services for minority populations is costly and there are various difficulties associated with determining eligibility of the different communities for the development of their own service. Previous research indicates that treating patients in the community itself is a large step towards addressing the issues which lead to delays and non-completion.³³

Alongside patient and community education, utilising trained community volunteers, makes treatment more accessible and decreases the problems associated with stigma

through the public nature of treatment.³³ As low adherence to prescribed medication was an important finding of this study (related to low or misinformation about TB treatment), health promotion activities aimed at providing culturally relevant and accessible information, combined with accessible service provision, would be the most appropriate intervention.

Table 2. Key recommendations for healthcare delivery to minority populations in the Waikato Health District

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- To assess the feasibility and costing of developing ethno-specific primary healthcare services to accommodate the cultural needs of minority populations.
 - To develop community based organisations and the training of community health workers for minority populations.
 - To improve the quality and effectiveness of communication of health professionals working with minority populations by developing:
 - A comprehensive professional interpreter service for primary healthcare services,
 - A national resource of reference material outlining appropriate cultural practices for each minority population,
 - A national electronic resource of health education,
 - Material for each minority population, and
 - Pharmacy systems which will produce drug prescriptions in English as well as in the patient's native language.
 - To facilitate specific professional training for health professionals working with minority populations.
 - To develop appropriate health promotion materials for each minority population after close consultation with these populations.
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Conclusion

Based on the findings of this study, and on a review of relevant international literature, the *Refugee and New Migrant Strategic Plan – 2002 to 2007* may need to be modified further.¹³ Recommendations from this study are presented in Table 2.

Social and cultural diversity is an important issue for health services in a multicultural society. This paper indicates that there is a perception amongst community representatives that their minority population groups experience disadvantage in accessing health services.

Whilst the development of ethno-specific health services within a mainstreaming health service environment would require a substantial amount of funds for relatively small population groups, simple measures such as community and patient education (undertaken by trained volunteers from the community) needs to be explored. Health services also need to recognise that there are both similarities and important

differences among the various African, Asian, and Pacific minority populations regarding their understanding of TB and of their approach to health services.

The implications of this challenge (improving access of indigenous and immigrant populations to health services) for the current TB control program in the WHD is equally relevant to TB control in other parts of New Zealand and in other countries with a low national prevalence of TB. Similarly the recommendations developed through this research may have equal applicability as a means of achieving improved access to health services by minority populations.

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