

Knowledge and attitudes to leprosy of Pacific People living in New Zealand

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Summary Leprosy persists in many Pacific countries, but attitudes and knowledge of leprosy among Pacific communities have not been well investigated. The lack of disease knowledge and stigma are major barriers to implementing case-finding strategies and prophylaxis programmes designed to eradicate leprosy.

A survey of Pacific Island adults aged 18 years and older, and living in Christchurch, New Zealand (NZ) was conducted using a validated stigma assessment tool (EMIC score) and a questionnaire on knowledge of leprosy and acceptability of prophylaxis.

A total of 117 Pacific adults (mean age 41, SD 14) completed the survey. Of these, 73% identified with Tongan ethnicity and 20% were NZ-born. The mean EMIC score was 18 (SD 9). Higher stigma scores were associated with older age, migrant status, Tongan ethnicity and those who knew someone with leprosy.

The cause of leprosy was not known by 82% of participants, 74% perceived that leprosy was a very infectious disease, 82% thought that leprosy was a severe disease and 73% thought that leprosy was difficult to treat. Family members (82%) were identified as most at risk of contracting leprosy than close social contacts (26%) and neighbours (22.0%). Family members (93%) were a priority for prophylaxis followed by close social contacts (27%), neighbours (25%) and others (12%).

Leprosy remains highly stigmatised among Pacific Islanders living in NZ which may increase the reluctance for offering prophylaxis to non-family contacts. This will contribute to the difficulty in eradicating leprosy by both case-finding and offering prophylaxis to contacts unless stigma can be reduced substantially.

Introduction

The stigma of leprosy has been present from ancient times and remains an important obstacle to the successful eradication of this disease and management of sufferers who have been treated but have persisting disfigurement.¹ Despite the fact that the infection can be cured negative attitudes persist, and are related to the external manifestations of the disease, cultural and religious beliefs, fear of transmission, an association with people considered inferior, and consequences of public health-related interventions such as patient isolation.^{2,3} Although the causes of stigma are complex there are similarities across both countries and cultures, with linkages to particular cultural contexts.^{2,4,5} In the Pacific region (island countries in the ethnogeographic region of Polynesia- Figure 1⁶) where conditions in leprosaria were poor, such as in Tonga and Samoa, or had been set up in old prison sites and patient movement was restricted, as occurred in New Caledonia.⁷ There was less stigma found where there had been more openness and dissemination of knowledge about leprosy such as in Fiji and Vanuatu.

In the Pacific region there is evidence of resurgence in the number of cases in Kiribati, after almost reaching the elimination target, set by WHO, of less than 1 case per 10,000 of the population in 2003.⁸ In other nations, such as Samoa low numbers of cases persist, and in the Solomon Islands civil unrest has disrupted control programmes. The ongoing identification of cases in New Zealand (NZ), Australia, USA and other developed countries among migrants from Pacific Islands has also raised concern that the spread of leprosy is continuing and

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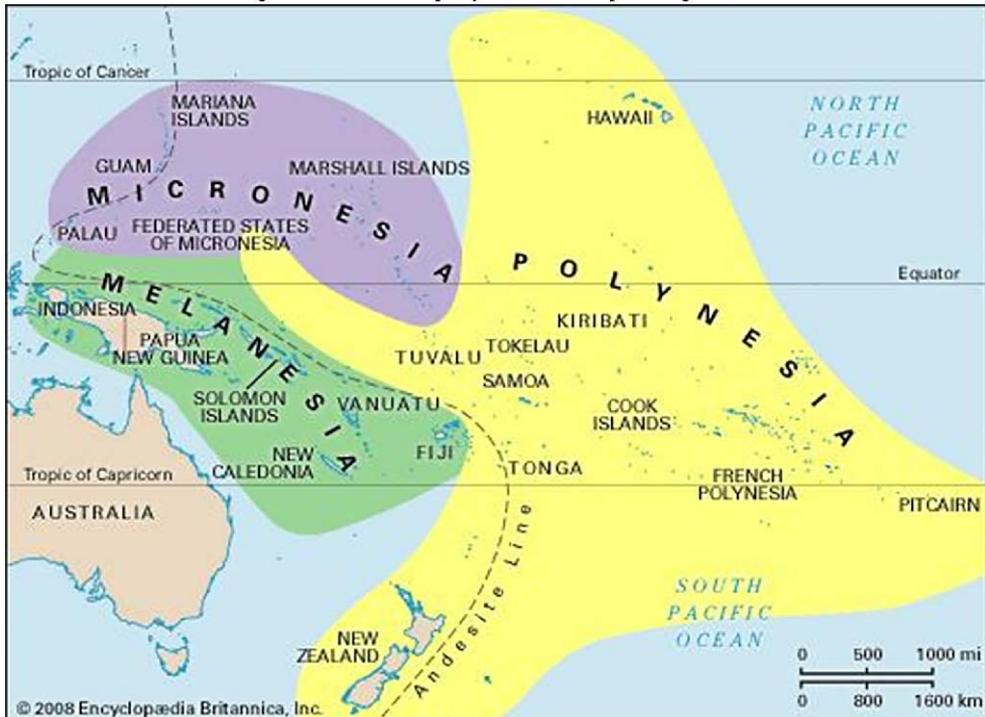


Figure 1. Map of the Pacific region divided into three ethnogeographic regions. Within the Polynesian region (yellow area) are the island countries from which a large proportion of New Zealand’s Pacific population descend (6).

control efforts need to be intensified.^{9,10} The results of surveys in Bangladesh and India also indicate that a large number of undiagnosed cases remain.^{11,12} Modelling of the numbers of cases expected and reported world-wide suggests that many cases are now not being identified, potentially setting the scene for a more widespread resurgence in cases.¹³

The cornerstones of a strategy to control leprosy are efficient case detection, contact tracing and treatment. The value of the addition of chemoprophylaxis has been demonstrated and proposed as a tool to prevent the occurrence of new leprosy cases among contacts by the Novartis Foundation for Sustainable Development and the World Health Organization (WHO).^{14,15} Unfortunately, the effectiveness of both contact tracing and chemoprophylaxis, which may lead to the index case being identified, could be compromised by the stigma of leprosy in the target community.

To understand the severity of any persisting stigma and how this might affect future control efforts we undertook a convenient sample survey among Pacific Island adults living in Christchurch, NZ which has a significant population of Pacific peoples who have similar demographics to Pacific in other regions of NZ.¹⁶ In addition the investigators have developed important linkages and high levels of trust with the Pacific community that are required to conduct this research. The primary tool was the EMIC scale that has been validated and used in several countries and is the recommended instrument for measuring leprosy related stigma by The International Federation of Anti-Leprosy Association (ILEP) and the stigma research workshop held in Amsterdam in 2010.^{17–19} In addition we assessed knowledge of leprosy and attitudes to chemoprophylaxis among the subjects by a questionnaire.²⁰

Methods

The study was cross-sectional in its design and included adults (aged > 18 years) who self-identified with any Pacific Island ethnicity (Samoan, Tongan, Cook Island Maori, Tokelauan, Tuvaluan, Fijian etc.), did not have leprosy and resided in the metropolitan area of the city of Christchurch, NZ. The total population of Christchurch is about 420,000 people of whom approximately 11,000 self-identify as Pacific People.²¹ Participants were recruited by word of mouth and by asking participants to suggest other possible subjects both within and outside their social group. Ethics approval was granted by the University of Otago Human ethics committee. Written informed consent was obtained from all subjects. The study was conducted between 1 November 2014 and 31 January 2015 and funded by the Pacific Leprosy Foundation (Christchurch, NZ).

A questionnaire was developed to assess socio-demographic characteristics and knowledge about leprosy. We incorporated the Explanatory Model Interview Catalogue (EMIC) scale to elicit illness-related perceptions, beliefs and practices.¹⁶ This comprises 15 items related to perception of stigma towards leprosy with each EMIC item scored as 'Yes = 2, Possibly = 1, No and Don't know = 0'. Eight questions were asked to determine participant's knowledge of leprosy including knowledge of the cause(s) of leprosy, leprosy infectivity, leprosy transmission, leprosy treatment, leprosy signs and symptoms and physical complications of leprosy. In this section, lead questions required a Yes/No response. Participants that responded with Yes were asked to provide further information selecting options from a populated list. Similarly, participants were asked to select groups they

perceived were most at risk of contracting leprosy and groups who would benefit from chemoprophylaxis.

The questionnaires were available in English and relevant Pacific Island languages. Questionnaires could be completed by either a face-to-face interview, an online survey, or filling in a hard copy at the discretion of the investigators. A trial of the questionnaire was conducted on a small number of subjects to assess acceptability and intelligibility among Pacific people and was modified according to feedback. Survey data was entered real time using the REDCap web-based survey and database software where possible.

A total of 120 participants entered the study and each provided written consent. Three participants were excluded from analyses because the age criteria was not met or EMIC scores were missing. Therefore a total of 117 participants with complete data were utilised in the analyses.

Statistical Analyses: Statistical analyses were performed using SPSS Version 22. Descriptive statistics (frequencies, means, medians and standard deviations) were used to describe the sociodemographic characteristics and the level of knowledge about leprosy. Chi-square and analysis of variance (ANOVA) tests were used on normally distributed variables. Differences in total perceived stigma score using EMIC between different groups were analysed using the Mann Whitney U test and Kruskal Wallis H test since these scores were not normally distributed. Cronbach's alpha test was used to determine the internal consistency of the EMIC questions.

Results

Table 1 shows the demographic characteristics of 117 participants included in this study.

Sixty seven participants were female (57%), 86 were of Tongan ethnicity (73%) and 93 were born in the Pacific islands (79%). The mean time migrants had lived in NZ was 22.8 years (SD 11.8). The mean age of participants was 40.8 years (SD 14.4) and on average they had 10.3 (SD 3.7) years of education. Approximately one in five participants had attended university. Sixteen subjects (14%) knew someone who had suffered from leprosy.

STIGMA

The results of the EMIC questionnaire are shown in Table 2.

Over 50% of participants thought that leprosy would greatly affect people's livelihood, cause shame or embarrassment, social isolation, difficulties for the family and problems finding work. Importantly more than half (53%) thought there would be problems of disclosure if a family member had leprosy and 46% thought a person with leprosy would keep others from knowing about this.

The median stigma score was 20.0 (range 0–30) and mean 18.6 (SD 9.1), with higher scores indicating a higher degree of stigmatisation of leprosy. There was internal consistency in the EMIC component (Cronbach's $\alpha = 0.940$). Twenty participants (17%) had the maximum stigma score of 30. The EMIC scores were not associated with gender ($P = 0.166$), the number of years lived in New Zealand ($P = 0.718$), years of education ($P = 0.191$) or university attendance ($P = 0.097$). Strong stigma scores were observed in participants aged 40 years and older compared to younger participants ($P < 0.01$). Being born in the Pacific

Table 1. Demographics of Pacific participant and comparisons of EMIC scores, $N = 117$

Characteristics	<i>n</i> (%)	Median EMIC score	<i>p</i> value*
Male	50 (42.7)	23.5	0.166
Female	67 (57.3)	17.0	
Age (mean, SD)	40.8 (14.4)		
< 40 years	54 (46.2)	13.5	<0.01
> 40 years	63 (53.8)	24.0	
Education			
Years of education \leq 13 years	102 (87.9)	21.5	0.191
Years of education $>$ 13 years	14 (12.1)	15.0	
Attended university	24 (20.5)	14.0	0.097
Did not attend University	93 (79.5)	21.5	
Marital status			
Married	81 (69.2)	21.0	0.166
Single	29 (24.8)	16.0	
Divorced	3 (2.6)	26.0	
Widow/widower	2 (1.7)	20.5	
Ethnicity			
Samoan	27 (23.1)	13.0	0.013
Tongan	86 (73.5)	24.0	
Fijian	4 (3.4)	19.5	
Country of birth			
New Zealand	24 (20.5)	13.0	<0.01
Samoa	18 (15.4)	12.0	
Tonga	71 (60.7)	24.0	
Fiji	4 (3.4)	19.5	
Years lived in NZ (migrants), mean (SD)	22.8 (11.8)		
Living in NZ for \leq 20 years	39 (50.0)	24.0	0.718
Living in NZ for $>$ 20 years	39 (50.0)	24.0	
Number of languages spoken			
One (English or Pacific Island language (Samoan, Tongan, Fijian))	14 (12.0)	20.5	0.879
Two (English and one Pacific Island language)	99 (84.6)	20.0	
Three (English and two Pacific Island languages)	4 (3.4)	21.0	
Knows someone with leprosy	16 (13.7)	25.0	0.026
Does not know someone with leprosy	101 (86.3)	17.0	

*Kruskal-Wallis and Mann-Whitney-U tests. Significance $p < 0.05$.

Islands ($P < 0.01$) and particularly those of Tongan ethnicity had significantly higher stigma scores compared to other Pacific ethnicities (Table 1).

People who reported knowing someone with leprosy also had higher stigma scores.

KNOWLEDGE OF LEPROSY

Twelve percent of those surveyed had ever received specific information on leprosy. The main sources were from the internet or school (36%), hospital (29%), friends or family (21%), health centres (14%) or the media (TV, radio, newspapers) (7%). Median EMIC scores were higher for those who had received information about leprosy compared to those that did not, however this difference was not statistically significant (EMIC median scores 24.5 vs. 19.5 respectively, $P = 0.435$).

Eighty seven (74%) participants thought that leprosy was a very infectious disease and 96 (82%) believed that leprosy was a severe disease. Only 21 (18%) reported that they knew

Table 2. Response YES to the EMIC questions in the NZ Pacific cohort, *N* = 117

Question	<i>N</i> (%)
Would a person with leprosy keep others from knowing, if possible?	54 (46.2)
If a member of your family had leprosy, would you think less of yourself, because of this person's problem?	42 (35.9)
In your pacific island community, does leprosy cause shame or embarrassment?	73 (61.9)
Would others think less of a person with leprosy?	59 (50.1)
Would knowing that someone has leprosy have an adverse effect on others?	56 (47.9)
Would other people in your community avoid a person affected by leprosy?	61 (51.7)
Would others refuse to visit the home of a person affected by leprosy?	48 (40.7)
Would people in your community think less of the family of a person with leprosy?	48 (40.7)
Would leprosy cause problems for the family?	67 (56.8)
Would a family have concern about disclosure if one of their members had leprosy?	62 (53.0)
Would leprosy be a problem for a person to get married?	58 (49.2)
Would leprosy cause problems in an on-going marriage?	51 (43.2)
Would having leprosy cause a problem for a relative of that person to get married?	50 (42.4)
Would having leprosy cause difficulty for a person to find work?	63 (53.4)
Would people dislike buying food from a person affected by leprosy?	75 (63.6)

the cause of leprosy. Of these participants, 19 stated that bacteria was the cause of leprosy whilst the remainder thought that there was another unspecified cause. Almost a third of participants (38, 33%) reported to know how leprosy was transmitted, and of these 35 (90%) knew that it was transmitted from an infected person.

Table 3 shows that high stigma scores were significantly associated with the perception that leprosy is a very infectious disease, is difficult to treat and is a severe disease.

One quarter of participants reported that they knew the signs and symptoms of leprosy. Twenty eight respondents (24%) reported knowing what the signs and symptoms of leprosy were with 10 participants recognising only one sign and symptom and 18 recognising two or

Table 3. EMIC scores associated with knowledge of leprosy, *N* = 117

Variable	Yes, <i>N</i> (%)	Median EMIC score	<i>p</i> -value*
Leprosy is very infectious	87 (73.1)	24.0	
Knows how leprosy is transmitted	39 (32.8)	26.0	<0.01
<i>Infected person*</i>	35		
<i>Mosquito*</i>	2		
<i>Water/soil contamination*</i>	1		
<i>Other*</i>	1		
Leprosy is difficult to treat	85 (71.4)	24.0	<0.01
Leprosy is a severe disease	96 (80.7)	23.0	<0.01
Knows the signs and symptoms of leprosy	29 (24.6)	19.0	0.734
<i>Discoloured patches on the skin*</i>	23		
<i>Tingling*</i>	4		
<i>Loss of sensation on the skin*</i>	14		
<i>Deformity*</i>	9		
<i>Ulcer*</i>	15		

*These options were only answered by participants who responded YES. Multiple options were able to be selected. Kruskal Wallance H and Mann-Whitney-U tests were used to determine associations between each variable and the EMIC scores. Significance *p* < 0.05.

more signs and symptoms. The stigma scores were high whether or not the person knew the physical manifestations of leprosy (EMIC scores 19.0 vs. 20.5 respectively, $P = 0.444$). Eighty five participants (73%) thought that leprosy was difficult to treat. EMIC stigma scores were significantly higher for those who perceived leprosy to be an infectious disease compared to those who did not (EMIC score 24.0 vs. 11.0 respectively, $P < 0.01$).

CHEMOPROPHYLAXIS AND LEPROSY

Ninety-seven (82%) reported that leprosy was more likely to be spread to others who are in close, frequent contact with someone who has leprosy. The people most likely to be at risk of developing leprosy were family members (91, 77%), close social contacts defined as having contact of at least 4 hours, 5 days per week (31, 26%), neighbours (26, 22%) and others (6, 5%).

Ninety three percent ($N = 110$) of respondents thought that family members of a person with leprosy should be offered prophylaxis with less than one-third reporting that it should be offered to close social contacts (32, 27%), neighbours (30, 25%) and others (14, 12%).

High concordance between groups at risk of leprosy and those who would benefit from prophylaxis was observed. Ninety-eight percent agreement was observed for family members, 77% for neighbours, 71% for close social contacts and 50% others. Stigma scores were higher for those who selected that family members be offered prophylaxis (22.0 vs. 10.0 respectively, $P < 0.01$), however, there were no differences observed for neighbours or close social contacts.

Discussion

The results of this survey indicate that there is a continuing deep seated stigma associated with leprosy among Pacific Islanders, particularly among Pacific migrants, living in New Zealand (NZ). This was evident irrespective of how long they have lived in NZ, or educational level. The most likely explanation is that it may reflect attitudes that have been acquired from their cultural background. The degree of stigma as measured by the EMIC questionnaire was quite severe with a median of score of 20. This compares unfavourably with a median score of 12 among members of the community living in the Pokhara municipality of western Nepal around a leprosy hospital, and with a stigma score of 10 among patients with leprosy in the same district.²² This suggests that changing attitudes faces a particular challenge in Pacific people.²³

The relative lack of knowledge of the disease development such as how leprosy was transmitted, the cause of leprosy and specific signs and symptoms of leprosy was not surprising given that participants were now living in a low prevalence area. Low levels of knowledge have also been described among leprosy sufferers and their families as well as the healthcare profession at sites where leprosy is endemic.²⁴⁻²⁶ It is also not surprising that only 12% had received specific information about leprosy. In a similar study performed in the community around Pokhara only 28% had received specific information on leprosy although there is a leprosy hospital there and contact with patients was common. In Tamil Nadu, only about one third of patients and their families knew that leprosy was caused by a germ.²⁶ While these results may not accurately reflect the knowledge base of those living in Pacific

Island countries where leprosy is more common than in NZ, it is likely that there is large knowledge gap that needs to be addressed in countries where leprosy persists.

Of concern is the number of participants who thought that leprosy was a very infectious disease (74%), difficult to treat (73%) and a severe disease (82%) which were much higher proportions than those recorded in the community in Pokhara which were 20%, 36%, and 60% respectively.²² These views have been strongly associated with high stigma scores and if they are present in Pacific Island countries, they will need to be specifically addressed.²⁷ These attitudes may reflect in part a lack of dissemination of relevant information but are likely to have been reinforced historically by the public policy of isolating patients to control spread. Provision of information alone is unlikely to be sufficient to change attitudes significantly without some constructive engagement with the communities at a local level.²⁸

An encouraging result was the finding that most respondents would accept chemoprophylaxis against leprosy being offered to family members. Prophylaxis for neighbours, close social contacts or others in the community were a lower priority. Associated stigma scores suggest that fear of the social consequences may have contributed to this choice. Disclosure creates a dilemma between the increased possibilities of care but is linked to the possibility of negative feelings, isolation and social stigma.²⁹ However, this is a similar pattern to that found in Bangladesh among healthy people from both rural and urban communities where participants would not object to disclosure of the diagnosis to family members but were not willing to share this with neighbours or other social contacts.³⁰ In that study all participants were willing to take chemoprophylaxis even if full protection was not guaranteed. Among Pacific respondents the tight concordance observed between those at risk and those who should be offered prophylaxis may indicate that being-at-risk is a stronger determinant of prophylaxis rather than stigma. Leprosy education to Pacific communities may assist in offering prophylaxis to contacts outside the family unit. Overall, these results indicate that chemoprophylaxis is an option worth considering as part of a leprosy management and control strategy.

This study has several limitations. The first is that 80% of participants were migrants found by word of mouth which means that the results may not be representative of the general Pacific Island community in NZ or in Pacific Island countries. Nevertheless the degree of stigma identified was striking and not apparently modified by the educational levels, place of birth and time living in NZ suggesting these are deeply held beliefs reflecting the cultures of origin. They are thus likely to persist in Pacific Island countries. Secondly, over 70% of participants were of Tongan ethnicity limiting applicability to other ethnic groups. Thirdly, the impact of complex cross-cultural beliefs and practices were unable to be assessed in this study because the study design was solely quantitative in nature. Lastly, we acknowledge that the total sample size ($N = 117$) is small, however these results are consistent with findings from studies in other countries suggesting the results are strong enough to require validation in Pacific countries where leprosy remains a problem and country specific strategies developed.

The results of this study, and other reports, have important implications for the development of leprosy control strategies in Pacific countries. Lack of disease knowledge is common and may make a major contribution to the persistence of stigma which is likely to be an impediment to case finding and integration of patients into society. However high stigma levels do not impede chemoprophylaxis being offered to family members, and other contacts if the index case is agreeable. This approach is relatively easy to implement as part of a comprehensive control strategy, but would reduce the efficacy somewhat. Chemoprophylaxis

would reach those most at risk, and may still be worth implementing in areas of low incidence. Alternatively chemoprophylaxis could be offered as part of a mass community based campaign to areas of high transmission without disclosure of the identity of the index case.³¹ The most appropriate strategy will need careful consideration in the specific setting.

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