

Comparing the perception of community members towards leprosy and tuberculosis stigmatisation

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Summary

Background: Health professionals at all levels gradually recognise the impact of stigma on case detection and treatment of various health conditions such as leprosy and tuberculosis. These diseases are identified as chronic diseases which are prone to stigmatisation.

Purpose: To assess the perception of community members towards stigma related to leprosy and tuberculosis, in order to verify and compare the existence of stigma towards these two diseases in the community, and to provide baseline data for the evaluation of future de-stigmatising interventions.

Methods: This study was done in four sub-districts of Chaiyaphum province. Community members were interviewed using the EMIC stigma scale. Frequency was used to identify the percentage of community members who perceived stigma. A T-test was applied to compare the mean EMIC scores of community members between leprosy and tuberculosis. A *P*-value of <0.05 was considered indicative of a statistically significant difference or association.

Results: It was found that community members perceived that people affected by leprosy or tuberculosis were stigmatised by the community. However, community members perceived more stigma towards leprosy than towards tuberculosis, particularly in terms of shame, embarrassment, and problems in getting married. The difference was highly significant (*P* = 0.001, paired t-test).

Conclusion: The community's perceived stigma against people affected by either leprosy or tuberculosis may affect many aspects of their lives. The authors

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recommend use of strategically targeted de-stigmatising interventions that take local attitudes and perceptions into consideration.

Introduction

Health professionals at all levels recognise the impact of stigma on case detection and treatment of various health conditions, among which are leprosy and tuberculosis.¹⁻³ These diseases are commonly identified as chronic diseases that are prone to stigmatisation.⁴ Stigma attached to leprosy is caused by wrong beliefs about its causes, by its visible lesions or disfigurement, and by people's fear of infection and exclusion.⁵⁻¹⁰ Stigma attached to tuberculosis is caused by the severity of the illness, the public's fear of contagion through casual transmission, and by being confused with HIV/AIDS, which is associated with perceived sexual misconduct.¹¹⁻¹³ Many attempts have been made to reduce stigma attached to leprosy and tuberculosis.¹⁴⁻¹⁶ For instance, leprosy and tuberculosis services have been integrated into the general health care system to reduce the differences between people suffering from these diseases and those suffering from other conditions. In Thailand, the term 'Anaesthetic skin disease' was recommended for use in Education and Communication (IEC) instead of 'leprosy'.¹⁴ Moreover, a large budget has been used in the effort to reduce stigma attached to leprosy and tuberculosis conditions through IEC.¹⁷⁻¹⁹

However, it is unclear whether stigma attached to leprosy and tuberculosis actually decreased as a result of these efforts. Stigma is still present. Recently, in Thailand, leprosy-affected persons were still reported to be stigmatised by their neighbours and by health providers.²⁰ Some leprosy patients were shunned and refused treatment of their ulcers by nurse aides, resulting in delay in diagnosis and poor compliance with treatment for many of them.²¹ In the same country, tuberculosis patients perceived tuberculosis as a dreadful, disgusting disease of death. They responded to this perception by denying the truth and by isolating themselves.²² Those affected by leprosy and tuberculosis who have visible symptoms of their disease are not eligible to apply for certain types of work.²³ In some areas in Indonesia, leprosy was feared so much as a disease that patients and health workers sometimes avoid mentioning its name, because of its association with deformity and stigmatisation in the community.⁸ In Nepal, when infections become known to others, some people affected by leprosy would withdraw from social life.²⁴ In Pakistan, stigma related to tuberculosis diminished marriage prospects of young tuberculosis patients and their family members.²⁵

The aim of this study was to assess the perception of community members regarding stigma related to leprosy and tuberculosis in order to verify and compare the existence of stigma towards these two diseases in the community and to provide baseline data for the evaluation of future de-stigmatising interventions.

Methods

Four sub-districts of Chaiyaphum province were selected as the study area because of the relatively high prevalence of leprosy there. The sample size of respondents was calculated based on an estimated prevalence of community members who have negative attitudes towards leprosy of 96% found in a study of Srisak and the desired width of the 95%

confidence interval of $\pm 1-5\%$.^{26,27} A total of 236 of community members who lived in the same village as people affected by leprosy and people affected by tuberculosis were selected by systematic sampling, which was conducted by obtaining a list of names from a local health officer. The number of eligible people of each sub-district varied from 500 to 700. As the required number of respondents was 60 from each sub-district, every 8th-11th name in the list was selected. Before use, the data collecting tool, the Explanatory Model Interview Catalogue (EMIC) scale, had been translated into Thai by a researcher who was responsible for leprosy-related rehabilitation and back-translated into English by an outsider who was not related to either leprosy or rehabilitation work to ensure that the meaning of the original items was correctly translated. The tool was piloted among 30 community members with similar characteristics as the study groups. The experience gained during the piloting of the tool was used to adjust the statements that were not completely understood by the respondents.

The EMIC scale consists of 15 questions covering different aspects of stigma. Each has four answer options: ‘yes’, ‘possibly’, ‘no’, and ‘don’t know’. The scores for each answer are 2,1,0,0 respectively. We chose a cut-off point for ‘perceived stigma’ of 8, which means that the respondents are considered to perceive stigmatisation in the community when they answered at least four questions with ‘yes’, or eight questions with ‘possibly’, or the combination of both answers with a sum score of eight. The reason for choosing a relatively high score of eight was to increase the specificity of the cut-off point. If a respondent answered ‘yes’ or ‘possibly’ to fewer questions, there would be a high risk of false positive classification, that is of drawing the conclusion that someone perceives stigma too easily.

A frequency distribution was used to determine the percentage of community members whose EMIC score was equal or greater than eight. A paired T-test was used to compare the EMIC score of community members regarding leprosy and tuberculosis.

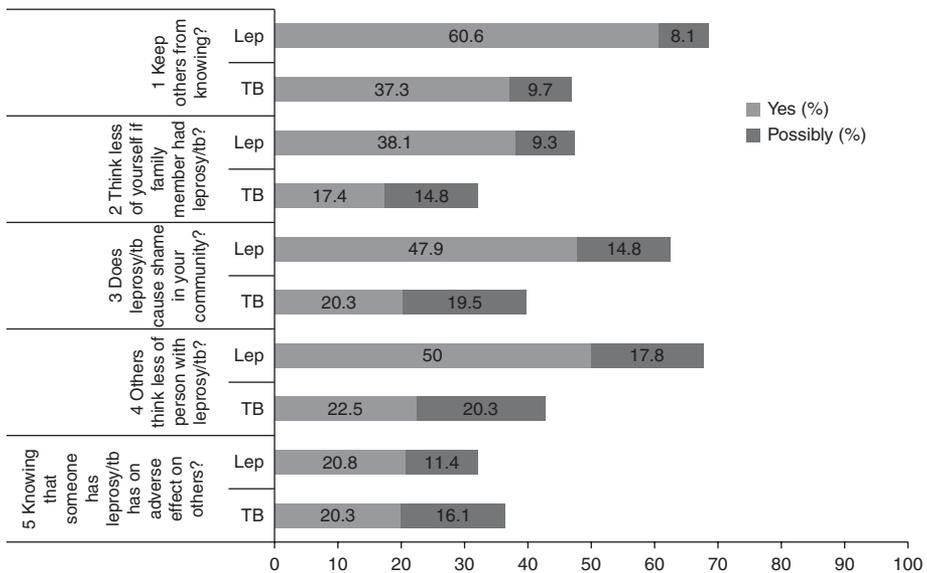


Figure 1. Perception of stigma among CM towards leprosy and tuberculosis; item 1–5

Results

CHARACTERISTICS OF THE COMMUNITY MEMBERS

Of the 236 community members interviewed, 153 (64.8%) were female, 163 (69.1%) completed only primary school, 186 (78.8%) were married, and 186 (78.8%) were aged between 18 and 84 years.

The percentage of community members who perceived negative attitudes and behaviour against leprosy was 75.4, while the percentage who perceived the same for tuberculosis was 54.7. The mean EMIC score for leprosy was 15.4 (95% CI 14.3–16.6), while that for TB was 10.6 (95% CI 9.5–11.7). The difference was highly significant ($P = 0.001$, paired T-test).

Figure 1 demonstrates the views of community members on how they and other people feel in having people affected by leprosy and tuberculosis in their family or community. More than 60% thought that people with leprosy would keep others from knowing their condition, that leprosy would cause shame, and that others think less of people with leprosy. In contrast, only about 40% had these thoughts regarding people affected by tuberculosis.

Figure 2 shows that more than 60% of community members believed that community members avoid a person with leprosy, and thought less of the family of people with leprosy; while significantly fewer people had the same thoughts regarding people affected by tuberculosis.

Figure 3 shows the views of community members on how leprosy and tuberculosis affects people with leprosy and their families in terms of marital relationships and work prospects.

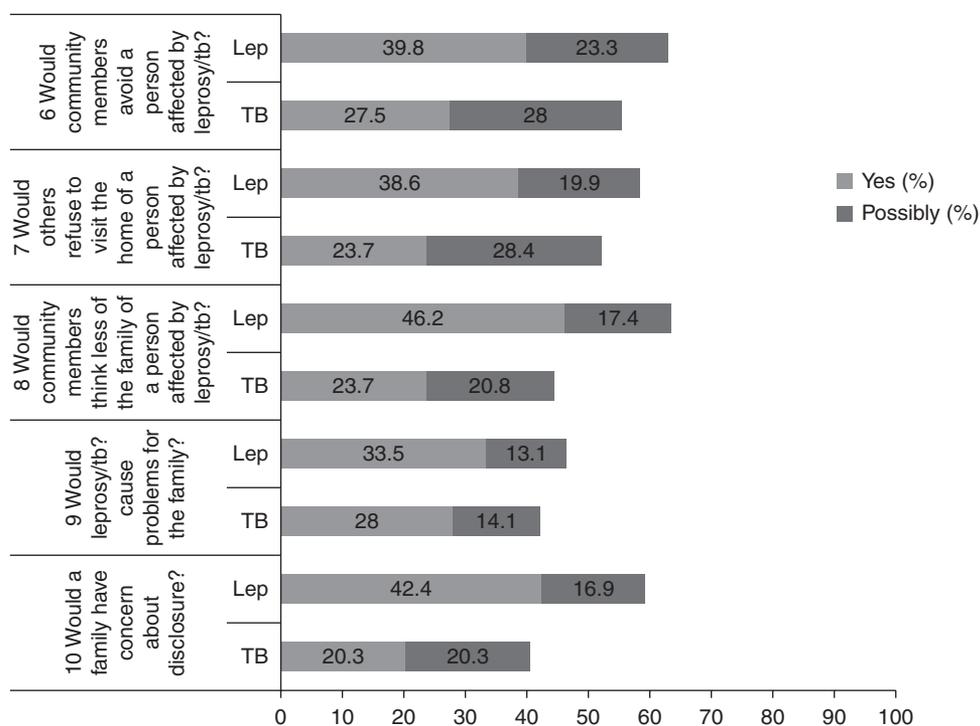


Figure 2. Perception of stigma among CM towards leprosy and tuberculosis; item 6–10

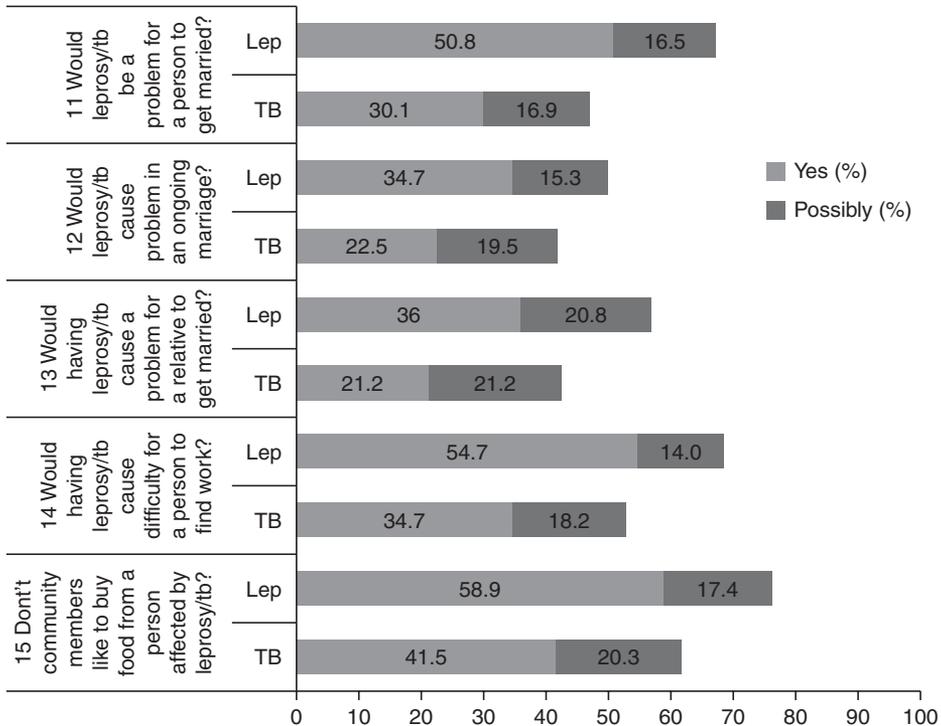


Figure 3. Perception of stigma among CM towards leprosy and tuberculosis; item 11–15

Over 60% thought that leprosy would be a problem for an affected person wanting to get married while fewer (46%) had the same thoughts regarding people affected by tuberculosis.

Discussion

Community members perceived negative attitudes towards people affected by leprosy or tuberculosis. A majority of respondents considered that both people affected by leprosy and people with tuberculosis were treated poorly by others in the community. The findings supported the study of van Brakel *et al.*, who found that communities in Indonesia perceived stigma against leprosy, and a recent study of Adhikari in Nepal, who reported high perceived stigma related to leprosy among community members.^{28,29} These findings are also consistent with the study of Liefoghe in Pakistan who found that tuberculosis is perceived as a very dangerous infectious and incurable disease, and the study of Wu who showed that health workers in India perceived community members to stigmatise people with tuberculosis.³⁰ We found stigma against leprosy to be stronger than that against tuberculosis, particularly in terms of shame or embarrassment, and in creating a problem in getting married. Forty-eight percent of community members thought that leprosy causes shame, while only 20% had the same view regarding tuberculosis; 50% agreed that others think less of people with leprosy, while 22.5% agreed that others think less of people with tuberculosis. Fifty-one percent answered 'yes' to the statement that leprosy would be a problem for a person wanting to get

married while only 30% answered 'yes' regarding tuberculosis. This stronger stigmatisation of leprosy may be because leprosy is used as a term to embarrass people in Thai society and is perceived as hereditary.³¹ Stigma related to leprosy affects people affected in both physical and socio-economic ways. (Stigma in leprosy: manifestations, effects and dynamics. Unpublished observation). However; the consequences of having tuberculosis are also miserable for people affected, as shown in the study of Manoonpanich in Thailand who found that as a result of the perception of stigmatisation, tuberculosis patients isolated themselves.²² The study of Liefoghe in Pakistan also found stigmatisation led to isolation of tuberculosis patients and their families including reduced marriage prospects for them. It is important to address stigma related to both diseases.²⁵

In the study of van Brakel, who reviewed stigma measurement in different disciplines, there were two studies reporting the association of leprosy with shame or embarrassment while there was only one that found this kind of association in tuberculosis.² In the same review, there was one study that showed that leprosy causes problems of getting married for the affected person, while there was none related to tuberculosis. However, this may also reflect the fact that relatively little research had investigated TB-related stigma at that date.

Based on her study in Kanchanaburi province of Thailand, Soonthorndhana mentioned that the stigma association with tuberculosis was perceived as less serious than that associated with leprosy.³² The majority of informants felt that tuberculosis was not a particularly stigmatised disease. However, many did point out that, if they knew somebody had tuberculosis they would protect themselves from becoming infected, but without discriminating against them. The study did not mention the reason why leprosy is more stigmatised. The current study found TB to be less frequently stigmatised than leprosy, but the perceived stigma level was by no means negligible. When examining the profile of stigma as presented in Figures 1–3, the pattern seems fairly similar to that of leprosy.

According to our literature reviews, the stronger shame and embarrassment related to leprosy may be attributed to the association of leprosy with disability and begging, characteristics that are already stigmatised.^{21,33} The stronger perception that leprosy causes problems to people affected in getting married may be because of the belief that leprosy is hereditary.⁸

Leprosy and tuberculosis are both ancient diseases. Their existence can be traced back thousands of years in the historical records.³⁴ Affected people have been stigmatised since the early days of these diseases. Stronger stigma against leprosy may have developed because leprosy was linked to people who are considered inferior.³⁵ For example the Chinese labourers employed in Hawaii were blamed for introducing leprosy into the country, while tuberculosis also affected people of high social class.³⁴ Due to the high prevalence of tuberculosis in the pre-antibiotic era, many prominent people developed or died from this disease. For example, the English romantic poet, John Keats (1795–1821) and some of his family were taken by tuberculosis.³⁴ Moreover, discrimination against leprosy was stronger than tuberculosis. People who had leprosy in the past were forced by law to live in leprosaria or colonies.³⁴ This forced exclusion reinforces stigma against leprosy.³⁶

The negative attitude of the community against people affected by either leprosy or tuberculosis affects many aspects of their lives, such as mental health, marriage and education, and timely and regular treatment.^{5,6,8,37–40} To promote an optimal quality of life of people affected by leprosy or tuberculosis, it is important to address stigma through tailor-made interventions that address the attitudes and perceptions of the local community.

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