

COMMUNITY-BASED INSIGHTS INTO LEPROSY STIGMA IN MALAYSIA: A COMPREHENSIVE STUDY INFORMED BY GLOBAL LITERATURE AND LOCAL PERSPECTIVES

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Abstract

Leprosy, a chronic dermatological disease, continues to afflict individuals worldwide, often accompanied by profound social stigma. This comprehensive study, set in Malaysia, aims to shed light on the pervasive issue of leprosy-related stigma within communities residing near the National Leprosy Centre. Drawing from both global literature and local perspectives, this research provides valuable insights into the complex dynamics of how leprosy is perceived and the resulting social consequences. Leprosy's societal portrayal transcends its medical aspects, often casting patients as social outcasts. While this curable ailment can be effectively treated with medication, misconceptions and fears persist. Such misconceptions often manifest as visible deformities, perpetuating negative attitudes and discrimination. This study delves into the Malaysian context, where leprosy's stigma remains a pertinent concern, albeit largely unexamined. Utilizing a cross-sectional approach, this research surveyed 260 individuals residing within a 4-kilometer radius of the leprosy center. Participants answered questions encompassing demographic, socioeconomic, and environmental factors, along with assessments of knowledge, attitude, and perceived stigma. The study identified a mean stigma score of 11.41, which, although lower than some global counterparts, underscores the existence of stigma within the community. Of particular significance, the study's findings revealed that negative attitudes held by community members played a pivotal role in driving leprosy-related stigma. Respondents with more unfavorable attitudes exhibited higher levels of stigma against leprosy patients. These negative attitudes stemmed from beliefs that leprosy is a chronic, highly contagious disease, despite contrary medical evidence. This research signifies the need for targeted awareness campaigns to dispel misconceptions and encourage empathetic, non-discriminatory attitudes towards leprosy patients in Malaysia. By leveraging insights

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from both local and global literature, this study contributes to the growing body of knowledge surrounding leprosy-related stigma and calls for community-based interventions to challenge and eradicate the deeply rooted stigma associated with this ancient disease.

Introduction

Leprosy is a chronic dermatological infection that has afflicted at least 100,000 people in the past. However, to date, the disease still affects millions in the form of new diagnoses and neurological defects (Lastoria et al., 2014). The disease is manifested in several types based on the clinical pathology spectrum of tuberculoid, lepromatous, paucibacillary or multibacillary in skin lesions (Eichelmam et al., 2012). Leprosy is still remaining endemic in most countries. In 2014, it was reported that 1000 new cases were detected from 14 countries. The three countries, India, Brazil and Indonesia, account for about 81% of all leprosy cases in the world. At the end of 2014, the world recorded a total of 213 899 new cases of leprosy, 3.8 cases per 100,000 inhabitants (World Health Organization [WHO], 2016). Leprosy is more associated with social illness than the term medical illness. This is because there is a misconception in society that there is a false perception of the reality of the disease since it was detected (Heynders, 2000). Although leprosy can be completely cured by the treatment of drugs, the misconceptions persist (Calcraft, 2006). In Nepal, the stigma against leprosy is still enduring. This condition exacerbates the psychosocial effects of being in the community after being diagnosed as the patient receives the physical effect of the disease on them (Van Brakel, 2003).

The disease has a physical effect on the patient who is later diagnosed and causes complications for physical disability. Misconceptions about the effects of leprosy lead to profound social stigma on leprosy patients. Visible deformities is one of the major contributing factors for stigma and further exacerbated by an attitude due to perceived fear of potential discrimination (Marahatta et al., 2018). Previous studies have shown that stigma causes infected patients to conceal the disease without seeking treatment to cause permanent disability (Rafferty, 2005). Leprosy-related social stigma is experienced by patients characterized as social exclusion, unacceptable in society, shameful and uncooperative in society (Ibikunle, & Nwokeji, 2017). It is generally known that there are many factors that interact and influence the level of stigma of the community against leprosy patients. When you know a person is infected with leprosy, there are various stigmas about the disease and negatively affect the patient. Although many studies have been done on the effects of this stigma, it is still not enough to correct the misconception of leprosy patients.

Studies on the stigma of people with leprosy are still underway in Malaysia. This situation leads to the need for research because the stigma against leprosy still exists and will not disappear as leprosy is cured. This is because leprosy has a very negative image and the stigma against it is a problem for leprosy patients (Barth-Jaeggi et al., 2016). However, in Malaysia there is still no published data on the study of community stigma against leprosy patients especially in the community around the leprosy centre which is very close to leprosy patients. The stigma of this society needs to be studied to improve understanding of knowledge, correct misconceptions about leprosy, non-discriminatory attitudes of leprosy patients, correct beliefs and practices in the practice that distinguish or isolate leprosy patients. By understanding this study, information about the stigma towards leprosy can be passed on to the general public and change the stigma against leprosy patients. Increased awareness of the effects of stigma should be done to help patients with leprosy, shy, marginalized and discredited. This study will determine the level of society's stigma score on leprosy patients in National Leprosy Centre (Pusat Kawalan Kusta Negara), by identifying the factors associated with the society's stigma score.

Methods

A cross-sectional study was conducted among the communities around the leprosy centre in Sungai Buloh as Aman Puri Village, Bukit Rahman Putra, Damansara Damai and Valencia from June to October 2019. A total of 260 persons were selected as respondents using sample random sampling for this three area. Respondent were adult aged 18 years and above who live near the Pusat Kawalan Kusta Negara in Sungai Buloh, Selangor in which within 4 kilometres of the centre. An individual from each selected family answered the survey questionnaire after obtaining consent to participate. Next face-to-face interviews are conducted. The questionnaire in Malay language and consists of information on demographic (age, gender, ethnicity, marital status), socioeconomic (education level, occupation, household income), environmental factors (location distance, family history of leprosy), knowledge, attitude and stigma score using validated EMIC questionnaire. The pilot study was conducted to determine the validity of the questionnaire used with cronbach alpha of 0.65, 0,81 and 0.66 for knowledge, attitude and stigma (overall cronbach alpha 0.75). Those who are selected but do not want to cooperate or get infected are excluded and new individuals will be selected within the family. Inclusion criteria and exclusion criteria were defined for this study. The inclusion criteria were individuals living around the leprosy center, Sungai Buloh, Selangor, individuals 18 years of age and above for both sexes and Malaysian. Exclusion criteria were individuals living temporarily around the leprosy center, Sungai Buloh, individuals who do not want to cooperate and provide information, people with leprosy and individuals who cannot speak Malay or English. Research approval has been obtained from the Secretariat for Medical Research and Innovation, National University of Malaysia Medical Centre. Approval of the study was obtained with FF Project Code - 2019 -250. Respondents were first informed of the background and purpose of the study and the confidentiality of the information provided in the questionnaire form. Respondents were also asked to sign the consent form as a voluntary sign to participate in the study. The sample size were calculated based on on Kish formula with 216 individuals after added 20% drop up. The data were analysis using pearson correlation, independent t-test and multiple linear regression to determine the factors associated with stigma score.

Results

The mean age of respondents was 25.49 (5.96) years. More than half of the respondents were found to be male (54.6%), Malays (73.1%) and not married (75%). Most of them were higher education status (82.4%), unemployed (53.2%) and had household income less than RM3860 a month (67.2%). In environment status, the mean placement distance for all respondents was 2.21 (1.27) kilometres.

84.3% of respondents received information about leprosy. It was found that the highest percentage of 66.5% of respondents received information from health centre followed by 11.5% of information from friends or family. The other 22% sources refer to information received from television or radio. Whereas information about the immediate family of the infected indicates that 100% of the relatives of the leper are not infected. Knowledge score majority of respondents had a high knowledge of leprosy (95.8%). A high percentage of this knowledge was related to knowledge of the cause of leprosy (79.2%), disease caused by bacteria or other organisms (77.4%), and contagious leprosy (88%). While the transmission of leprosy (74.5%) was caused by leprosy patients (87.6%). The highest percentage was non-chronic leprosy (92.1%) followed by severe leprosy (82.9%). However, knowing the signs and symptoms of leprosy was only (68.2%) which is a relatively low percentage. It is known that leprosy is a serious disease and leprosy is not a disease of 80% (91.7%) and (88%). The mean community attitude score for leprosy patients obtained in this study was 16.79 (4.55) out of a maximum of 28. All 7 attitude items showed mean score scores above 2 (> 2). The highest mean score is 2.89 which is for the attitude item "How do you feel about allowing someone like Pn. Salmah to be your nanny for a few hours? Whereas the lowest mean score is 2.09 which is for the item "How would you feel if you had a neighbour like Pn. Salmah?". The mean community

stigma score for leprosy patients was 11.41 (5.38) out of the maximum number of stigma scores in the questionnaire form 30. It was found, and only 4 items had a mean score less than one (<1). The item "Do family members worry if one family is infected with leprosy?" Was the highest mean of 1.44 while the lowest mean of 0.13 was for the item "Would you look down on this patient's leprosy family?". (Table 1). Only attitude showed a significant correlation with stigma score. Then interpret value of adjusted OR (0.365) (Table 2 and Table 3).

Table 1 Demographic, environment, knowledge, attitude and stigma score among community members living around leprosy center

Characteristics	Mean (SD)	n (%) (n=260)
Socio-demographic Factors		
Age (years)	25.49 (5.96)	
Gender		
Male		142 (54.6%)
Female		118 (45.4%)
Race		
Malay		190 (73.1%)
Chinese Indian		29 (11.1%) 26 (10.2%)
Others		15 (5.6%)
Marital Status		
Not married		195 (75.0%)
Married		65 (25.0%)
Socio-economic Factors		
Education Status		
Low		46 (17.6%)
High		214 (82.4%)
Occupational Status		
Employed		122 (46.8%)
Unemployed		138 (53.2%)
Household Income		
Low ($<$ RM3860)		175 (67.2%)
High (\geq RM 3860)		85 (32.8%)
	2.21(1.27)	
Environment Factors		
Placement Distance (KM)		
Receiving information about leprosy		
Yes		219 (84.3%)
No		41 (15.7%)
Source of information		
Health Centre		173 (66.5%)
Friends / Family		30 (11.5%)
Other (TV / Radio)		57 (22%)

The nearest family is infected		
Yes		0 (0 %)
No		260 (100%)
Knowledge		
Do you know the cause of leprosy?		
Yes		206 (79.2%)
No		54 (20.8%)
Source of Infection		
Microorganism		206 (79.2%)
Others		54 (20.8%)
Did you know, leprosy can infectious?		
Yes		229 (88%)
No		31 (12%)
Do you know the transmission of leprosy?		
Yes		194 (74.5%)
No		66 (25.5%)

The transmission		
Leprosy patient		228 (87.6%)
Contaminated environment		26 (9.9%)
Mosquito		5 (1.9%)
Others		1 (0.6%)
Do you think leprosy is difficult to treat?		
Yes		216 (82.9%)
No		44 (17.1%)
Do you think leprosy is a common disease?		
Yes		21 (7.9%)
No		239 (92.1%)
Do you know the signs and symptoms of leprosy?		
Yes		177 (68.2%)
No		83 (31.5%)
Sign and Simptom		
Grouped skin		88 (33.8%)
Sensitive Grouped Skin		90 (34.5%)
Weak foot and eyelids		-
Nervous		16 (6.1%)
Painless Pain		17 (6.8%)
Various		49 (18.9%)
Is leprosy a bad disease?		
Yes		238 (91.7%)
No		22 (8.3%)
Is leprosy a disease of divine punishment?		
Yes		13 (12%)

No		229 (88%)
Knowledge Score		
		10 (4.2%)
Low (<50) High (≥50)		250 (95.8%)
Attitude		
How do you feel about renting a room in your house to someone like Pn. Salmah?	2.20 (0.77)	
How would you feel if you were a colleague like Pn. Salmah?	2.12 (0.72)	
How would you feel if you had a neighbor like Pn. Salmah?	2.09 (0.73)	
How do you feel about allowing someone like Pn. Salmah to be your children's nanny for a few hours?	2.89 (0.97)	
What if one of your children wants to marry someone like Pn. Salmah?	2.79 (0.92)	
Are you going to introduce someone like Pn. Salmah to one of your male friends?	2.50 (0.85)	
Would you recommend someone like Pn. Salmah to work at your friend's company?	2.20 (0.84)	
Attitude score	16.79 (4.55)	
Stigma Score		
If necessary, is a person infected with leprosy hidden from other people's knowledge?	0.49 (0.82)	
If one of your family members is infected with leprosy, do you feel inferior?	0.37 (0.72)	
Does this leprosy cause you embarrassment in society?	0.84 (0.93)	
Do others look down on those with leprosy?	0.99 (0.90)	
Does knowing someone with leprosy harm others?	0.18 (0.55)	
Will you stay away from this leper?	0.63 (0.84)	
Would anyone avoid visiting a leper's home?	0.86 (0.89)	
Are you going to look down on this leprosy family?	0.13 (0.46)	
Will leprosy cause problems for their families?	0.57 (0.83)	
Do family members worry about having one family infected with leprosy?	1.44 (0.76)	
Does the patient have problems getting married if the patient is not married?	0.96 (0.86)	
Will leprosy suffer from problems in the household for married patients?	0.60 (0.84)	
Will leprosy cause problems for other family members to get married?	1.02 (0.84)	
Will leprosy patients have problems finding a job?	1.11 (0.96)	
Don't you like buying food from leprosy?	1.20 (0.82)	
Total Stigma Score	11.41 (5.38)	

Table 2 Factors associated to stigma among community members living close to leprosy center

Characteristic Factors	Score Mean (SD)	stigma t value	p value
Socio-demographic			
Age (years)	25.49 (5.96)	-0.005 ^a	0.937 ^b
Gender			
Male	11.26 (5.45)	-0.434	0.665
Female	11.58 (5.32)		
Race			
Malay	11.61 (5.34)	0.925	0.357
NonMalay	10.84 (5.44)		
Marital Status			
Not married	11.70 (5.35)	-1.405	0.161
Married	10.52 (5.43)		
Socio -economic			
Education Status			
Low	12.24 (5.45)	1.047	0.296
High	11.23 (5.35)		
Occupational Status			
Employed	11.63 (5.24)	0.578	0.564
Unemployed	11.21 (5.52)		
Household Income			
Low (< RM3860)	11.59 (5.31)	1.331	0.266
High (≥ RM 3860)	11.03 (5.55)		
Environment			
Placement Distance (KM)	2.21 (1.27)	0.025 ^a	0.714 ^b
Receiving information leprosy about			
Yes	11.47 (5.38)	0.411	0.820
No	11.06 (5.44)		
Knowledge of Leprosy			
Low (<50)	9.67 (5.00)		
High (≥50)	11.48 (5.39)		
Attitude Scores on Leprosy Patients		0.352 ^a	0.001^b
^a Correlation coeficien value (r) ^b Pearson's Correlation			

Table 3 Multiple linear regression analysis of factors associated on stigma among community members living close to leprosy centre

Factors	SLR ^a		MLR ^b	
	Crude b (95% CI)	p Value	Adj. b (95% CI)	p Value
Age	-0.005 (-0.13, 0.12)	0.937		
Gender	0.319 (-1.13, 1.77)	0.665		
Race	-0.925 (-2.59, 0.74)	0.275		
Marital Status	2.031 (-0.27, 4.34)	0.084		
Education Status	-1.332 (-3.26, 0.60)	0.175		
Occupational	-1.348 (-3.20, 0.50)	0.152		
Household Income	-0.370 (-2.63, 1.89)	0.746		
Placement Distance	0.201 (-0.39, 0.78)	0.499		
Information of Leprosy	-0.476 (-2.50, 1.55)	0.643		
Knowledge	0.373 (-0.09, 0.83)	0.110		
Attitude	0.399 (0.249, 0.55)	<0.001	0.365 (0.20, 0.53)	<0.001
a. Simple Linear regression b. Multiple Linear regression. ($R^2= 0.129$, The model is fix.: Assumption of model fulfilled: No interaction between independent variables and no multicollinearity problem)				

Discussion

The mean stigma scores among community living near to leprosy centre was 11.41 out of a maximum of 30. This shows that there is a perceived stigma in the community even though the disease has been around for a long time and the leprosy centre has grown. However, studies in some countries show higher stigma scores than this study. Similar studies conducted in Brazil show that stigma scores are 12.4 (Schutten, 2018) and in India are 13.8 (Rense et al., 2011). Both studies used EMIC to measure stigma scores in the study population. A study conducted in five regions in Indonesia also used EMIC-CSS and found that the mean stigma score was higher than this study which is between 13 – 16 (Van Brakel et al., 2012). Another study in the District of Cirebon, West Java, Indonesia also gave the highest mean score of 15.4 (Peters et al., 2014). The results of this study were lower than those of other countries because the study was concentrated only within 4 kilometer radius of the leprosy centre. The area cannot reflect the overall population of people living further than this study area. One-fourth of the area is also covered by the Bukit Lagong recreation area where no respondents are found in the area. In addition, it is possible that respondents did not answer every question that was provided due to time constraints. Although the time had been ample, the respondent was in a hurry. This creates a bias in the information obtained. Furthermore, this study requires researchers to devote more time to sampling throughout a wider area than the area around the leprosy centre to obtain information that is not possible due to time constraints.

These findings also indicate that stigma items that contribute most to stigma scores are from dislike of food from leprosy patients. This study shows results consistent with studies conducted in Indonesia (Sermitirong & Van Brakel, 2014). This is evidenced by a study (Adhikari et al., 2014) in Nepal, showing that a person's fear of infection leads to higher stigma. While the difficulty of getting a job is also seen as contributing to high scores. This is illustrated by findings consistent with a study conducted in Nonsomboon, Thailand (Kaehler et al., 2013) where patients were required to leave their jobs due to leprosy. Similar results were also obtained from the results of a study conducted in Nepal (Adhikari et al., 2014). That is, other family members are difficult to marry because they are influenced by leprosy conditions, which results from a study consistent with research done in Thailand (Kaehler et al., 2015).

The findings of this study found that only attitude factors influence the level stigma scores on leprosy patients. Respondents with high attitude scores had a negative attitude and had a stigma against leprosy patients. These findings are in line with some previous studies. Studies in Indonesia and Nigeria indicate that attitude factors are the major contributing factors to high stigma scores (Ibikunle, & Nwokeji, 2017; Peters et al., 2014). The results of this survey also found that majority of respondents had a negative attitude towards leprosy, which showed findings consistent with previous studies, as reported in Ethiopia (Tesema, & Beriso, 2015) and in India (Danturty et al., 2016). Similarly, higher stigma is found in people with a negative attitude toward leprosy. They think leprosy is a chronic disease, difficult to treat and a highly contagious infectious disease. Negative attitudes toward leprosy were found to be strongly associated with stigma in a study conducted in eastern Nepal (De Stigter et al., 2012).

Negative attitudes and high stigma are also shown in number of other diseases besides leprosy as tuberculosis (Sermitirong et al., 2015). The results of a recent study conducted in Thailand and India show a high negative attitude and stigma against tuberculosis which is considered to be a highly contagious disease in the community and cannot be cured (Soonthorndhana et al., 2000) while occupational health shows high stigma and negative attitudes toward tuberculosis patients (Wu, 2010). However, the study found that the stigma against leprosy was higher compared to the stigma against tuberculosis. This is because isolation of leprosy patients is performed while tuberculosis patients are not isolated (Mwasuka et al., 2018). Leprosy also involves the problem of finding a partner but has not been reported for tuberculosis. Therefore, the stigma of tuberculosis is less serious than the stigma of leprosy (Soonthorndhana et al., 2000). They argued that lepers would hide their disease, aimed at preventing it from being excluded by society. Attitudes to hide the disease can only be avoided if the public is provided with an accurate education of leprosy that can help the leper to be socially accepted and promote early treatment and prevent permanent disability.

Several limitations have been identified in this study. This study is limited to respondents who can speak Malay and English only. Therefore, information cannot be obtained primarily from respondents who are Chinese or Indian who can only speak Chinese or Indian. Similarly, Chinese or Indian respondents who are not fluent in Malay or English, the bias in the delivery of information can occur.

This study also is focused around a 4 kilometres radius of the Pusat Kawalan Kusta Negara. This study area cannot reflect the overall population of people living further than this study area. One-fourth of the area is also covered by the Bukit Lagong recreational forest area where no respondents are found in the area.

Conclusion

Stigma scores among community living in leprosy centre in Malaysia are lower compare to other countries. Negative attitude factors contribute to society's stigma against leprosy patients around the National Leprosy Centre. This negative attitude is driven by the notion that leprosy is a chronic and easily contagious chronic

disease. Although knowledge of leprosy is caused by microorganisms, there is still a negative attitude towards the patient.

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Conflict of interests

The authors declared no potential conflicts of interest.

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