ORIGINAL ARTICLE

Stigma and Depression among Tuberculosis Patients in Kedah, Malaysia

Amri NS[a], *Zakaria R*[a], *Mohamad N*[b]

[a]Family Medicine Department, School of Medical Sciences, Universiti Sains Malaysia, Health Campus, Kubang Kerian, Kelantan, Malaysia
[b]School of Dental Sciences, Universiti Sains Malaysia, Health Campus, Kubang Kerian, Kelantan, Malaysia

ABSTRACT

INTRODUCTION: Tuberculosis (TB) related stigma is one of the significant barriers in the global TB control programme and it may lead to depression. This study aims to assess the level of stigma among TB patients and its associated factors, as well as to ascertain the correlation between stigma and depression in Kedah, Malaysia. **MATERIALS AND METHODS:** This was a cross-sectional study using the proportionate sampling method. TB patients were recruited from respiratory clinics in three government hospitals in Kedah. Case report form, Malay version of TB stigma scale (TSS) and Beck Depression Inventory (BDI-Malay) were used for data collection. Data were then analyzed using the linear regression and correlation analysis. **RESULTS:** A total of 200 respondents were enrolled and the mean score of TB stigma from patient's perspective was 13.3 (6.87). Younger patient, currently married, higher education, unemployment, and HIV co-infection were significantly associated with the stigma experienced. 27.5% (n=55) of the TB patients were found to be depressed, with the majority categorized into mild severity (20%, n=40), followed by moderate (5.5%, n = 11) and severe depression (2%; n = 4). There was a moderate, positive correlation between stigma and depression which was statistically significant (r = 0.345, p<0.001). **CONCLUSION:** Although the stigma score among TB patients was not as high as has been postulated, there was a moderate, positive correlation between stigma and depression. Thus, the intervention to reduce the stigma among TB patients may be helpful as it may reduce the depression level.

Keywords
Tuberculosis, TB, stigma, depression

Corresponding Author
Dr. Rosnani Zakaria
Family Medicine Department, School of Medical Sciences, Universiti Sains Malaysia, Health Campus, Kubang Kerian, Kelantan, Malaysia
E-mail : rosnani@usm.my

Received: 8th November 2021; Accepted: 19th March 2022

Doi: https://doi.org/10.31436/imjm.v21i4

INTRODUCTION

Tuberculosis (TB) has become a major public health problem worldwide with an estimated 10 million cases and 1.3 million deaths in 2018.[1] It is listed as one of the top 10 causes of death globally and the single leading fatal infection above HIV/AIDS.[1] In Malaysia, the incidence of TB has fluctuated substantially in the current year with increment through 2000-2019 that resulted in 92 cases per 100,000 people in 2019.[1] TB affects not only the physical wellbeing of the sufferer, but also his or her mental health. Studies have shown that patients with TB often experience psychological distress, specifically social stigma and depressive symptoms which may impede their management process and quality of life.[2,3] This cohort of patients was subsequently prone to have impaired disease coping ability and poor treatment adherence which continues to be one of the significant barriers to the global TB control.[4,5]

Upon the diagnosis of highly infectious TB disease, on top of the symptoms, the patient may also suffer from social and economic discriminations related to the disease stigma.[6,7] Stigma is defined as discrediting attributes associated by certain condition that leads to an individual being disqualified from full social approval.[8] Weiss et al have recently defined health-related stigma as "social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem".[9] Stigma acts as a social determinant of health, found to be a major hindrance for patients to access medical care (hence leading to diagnostic delay) and proper disease management.[10,11]

Literature demonstrates that an estimated 47%-73% of TB

patients are stigmatised.[12,13] Among possible factors contributing to the TB related stigma are age, gender, education level, financial status, and the lack of TB knowledge.[14,15] In addition to this, TB stigma was prevalent primarily in pulmonary tuberculosis, having comorbid HIV infection, being in an intensive phase of treatment, having poor social support and substance usage e.g., alcohol and cigarette.[16]

TB patients report fears of isolation and rejection such as losing job, being divorced, or having diminished marriage prospects, being prevented from sharing food or utensils, and being afraid to become the focus of public embarrassment.[17,18] These patients felt ashamed to be with their family and in the community because they were carrying the infection and exposing everyone else to it, and they felt that others looked down upon them.[19,20] Fear of these consequences may cause many TB patients to hide their symptoms and their disease which subsequently contributes to diagnostic delay, more severe diseases at presentation and poorer prognosis.[7]

The psychological impact and stigma suffered by TB patients may predispose them to depression. Depression is a common mental disorder characterized by sadness, loss of interest or pleasure, guilt feeling or low self-worth, disturbed sleep or appetite, feeling of tiredness and poor concentration.[21] Evidence shows that people with tuberculosis often suffer from depression.[22,23] The prevalence of depressive symptoms in tuberculosis diagnosed cohort was documented to be variable across different continents as reported in India (39.5%), Ethiopia (43.4%), Pakistan (46.3%), Cameroon (61.1%) and Nigeria (41.5%). 2,4,5,24,25 In Malaysia, the prevalence of depression among tuberculosis patients was reported to be 7.7%. [26] Factors that are significantly associated with depression are HIV/TB co-infection, poor social support, and perceived TB stigma.[5,27,28] It was postulated that the people with perceived stigma might have a low self-image and be socially isolated, which may predispose them to depression.[29]

Tuberculosis related stigma remains one of the significant challenges in TB prevention programmes and may synergistically contribute to depression. Both stigma and depression among tuberculosis patients might be associated with poor outcome, treatment failure and an increase in TB burden. Until now, there is limited established local information about the level of TB stigma in Malaysia. Therefore, this study aims to evaluate the level of stigma, associated factors, and its relationship with depression amongst TB patients in Kedah, Malaysia. The data retrieved from this research should be able to increase our understanding of tuberculosis related stigma and depression, guide us to determine the point of action for intervention and thus strengthen our National TB Prevention and Control program.

MATERIALS AND METHODS

A cross-sectional study was conducted at chest clinics providing TB services in three tertiary government hospitals in Kedah, Malaysia, from October 2019 to September 2020. Eligible participants were tuberculosis patients of Malaysian nationality above 18 years old, who were receiving TB treatment. The exclusion criteria include participants with language barrier and those who were suffering from a psychiatric illness that could compromise their ability to give informed consent. For illiterate patients, the interview was assisted by the researcher.

The sample size was calculated using Power and Sample size calculation (PS) Software using the comparison of 2 means methods for categorical variables. The standard deviation of the mean stigma score in the variable's monthly income was 8.0 (Lee et al) and taking detectable difference of 3.5, the sample size calculated was 166.[27] Considering the participant's non-response rate of 20%, the minimum sample size required was 208.

Data Collection

Data were collected using a standard structured anonymous questionnaire administered by a trained medical-based interviewer except for the last section which was self-administered by patient. The questionnaire item consisted of 3 sections: sociodemographic data and medical background, tuberculosis stigma scale (TSS) and Malay version of Beck Depression Inventory (BDI-Malay). The sociodemographic characteristics comprised of age,

gender, race, marital status, employment, education level and household income. Medical background included the history of current and prior TB treatments, if there is any, and concomitant comorbidities. These data were collected from the participant's case notes and partly from the interview.

TB-related stigma was measured via face-to-face interview using tuberculosis related stigma scale (TSS), which was adapted from Rie et al.[30] The 23- item TSS consists of 2 subscales: community perspectives towards TB stigma and patient perspectives toward TB stigma. In this study, only the latter subscale was used, which consists of 12 items. The score for each item was rated on a Likert scale with four levels; from strongly disagree (0), disagree (1), agree (2) and strongly agree (3). The responses were summed up to create stigma scores, and higher score indicates higher level of stigma. The score ranged from a minimum of 0 and the maximum of 36. The original scale has demonstrated satisfactory psychometric properties with good internal consistency (Cronbach's coefficient alpha ranging from 0.82 – 0.88) and fair test retest-reliability ($r=0.46$, $p=0.10$). The TSS was originally in English, thus it was translated to Malay language with author's approval via forward and backward translation before undergoing the reconciliation and harmonization process. A pilot testing using the Malay version of TSS was conducted among 30 TB patients to obtain reliability, validate the questionnaires and test on participant's understanding on the items. The pilot study revealed that the instrument has an acceptable validity and good reliability with Cronbach's Alpha value of 0.778.

The last section of the questionnaire assessed the degree of depression using Beck-Depression Inventory. This is a 21-question multiple choice self-reporting inventory developed by Beck et al.[31] The items are scored on a Likert scale ranging from 0 to 3, which denotes the severity of symptoms. Items 1 to 13 evaluate the psychological symptoms, while items 14 to 21 evaluate the somatic symptoms. The total BDI score shows the degree of depression, and higher score indicates a greater degree of depression. The original version of the BDI was translated into the Malay language and validated by Muhktar and Oei (32). One item (loss of libido) was removed for the BDI-Malay version due to cultural and religious perspectives, making the BDI-Malay comprise only 20 items. The minimum score of the tool is 0 while the maximum score is 60. The psychometric properties were established in the previous research with the internal consistency ranging from 0.71 to 0.91.[32] The permission to use this BDI- Malay questionnaire was obtained from the author prior to the study.

All TB patients who came for follow-up treatment at the chest clinic in 3 tertiary hospitals in the state of Kedah were screened for their eligibility for the study. Those who fulfilled the criteria were invited to participate in the study and informed consent was obtained prior to the study. The participants were given the assurance of confidentiality over their personal and medical information. Face to face interview was carried out in a secluded corner or room to ensure the participant's privacy when answering the questionnaires. Subsequently, respondents were given a self-reporting inventory BDI-Malay questionnaire to answer. Patients who were found to be depressed (of any stages) were then referred to the respective medical officer in charge, for further assessment and management.

Data analysis

Data were analysed using IBM SPSS Statistics Version 23.0. The categorical data were described using frequency and percentage while numerical data were presented as mean and standard deviation (SD). Assessment of normality was conducted using graphical method of histogram in this study. The empirical distribution of the data was bell shaped and resembled the normal distribution. Simple Linear Regression (SLR) tests were applied in the univariate analysis. Significant variables in the univariate analysis were selected for the multivariable analysis. Variables comparison with p-value less than 0.05 is considered significant.

Subsequently, a multiple regression analysis was run to predict the stigma score. Initially, a preliminary model consists significant variables of the univariate analysis. However, to achieve a parsimonious final model, the backward, forward, and stepwise selection methods were

applied using the SPSS software. All selected variables by the SPSS software in the final model were significantly predicted the stigma score in the multivariate analysis. All assumptions for the tests were checked. Lastly, a Spearman's rank order correlation was run to determine the relationship between stigma and depression score.

ETHICAL CONSIDERATION

This study was approved by the Human Research Ethics Committee of Universiti Sains Malaysia (USM/JEPeM/19080452) and Medical Research Ethics Committee of the Ministry of Health {NMRR-19-2495-50056 (IIR).

RESULTS

Out of 208 respondents, 8 were excluded due to incomplete data and questionnaires making a final total of 200 eligible tuberculosis patients were included into this study (response rate 96%). The mean age of the participants was 46.7 ± 16.6 years. Majority of the participants were Malays (83%), more than half were males (65%), single (65%) and employed (54%). Only 10.5% from the respondents earn more than rm3000 per month and 59% completed secondary education. Detailed sociodemographic and clinical data of respondents is shown in Table I.

Based on our assessment using tuberculosis stigma score (TSS), it showed that calculated mean stigma from the patient perspectives was 13.30 with a standard deviation of 6.87, whereas the mean depression score was 7.77 with standard deviation of 8.05. Our study also found that 27.5% (n=55) of TB patients were depressed, with majority of them categorized in mild depression (20%, n=40), followed by moderate severity (5.5%, n = 11) and severe depression (2%; n = 4) (Table II).

At univariate level, the stigma score was significantly associated with age, marital status, employment, education background and HIV status of the respondents (Table III).

Table I: Patient characteristics (n=200)

Variables		n	(%)	Mean	(SD)
Age				46.78	(17.11)
Gender	Male	130	(65.0)		
	Female	70	(35.0)		
Race	Malay	166	(83.0)		
	Non-Malay	34	(17.0)		
Marital Status	Single	130	(65.0)		
	Married	52	(26.0)		
	Divorced	18	(9.0)		
Employment	No	92	(46.0)		
	Yes	108	(54.0)		
Income	Less RM3k	179	(89.5)		
	More RM3k	21	(10.5)		
Education	Tertiary	39	(19.5)		
	Secondary	118	(59.0)		
	Primary/ No School	43	(21.5)		
TB Contact	No	158	(79.0)		
	Yes	42	(21.0)		
Types Of TB	Extra PTB	68	(34.0)		
	PTB	132	(66.0)		
Index TB	Previously Tx	27	(13.5)		
	New Case	173	(86.5)		
Phase of TB Treatment	Maintenance	102	(51.0)		
	Intensive	98	(49.0)		
HIV	No	186	(93.0)		
	Yes	14	(7.0)		
Comorbid	No	131	(65.5)		
	Yes	69	(34.5)		
Diabetes	No	151	(75.5)		
	Yes	49	(24.5)		
COPD	No	191	(95.5)		
	Yes	9	(4.5)		
Asthma	No	198	(99.0)		
	Yes	2	(1.0)		
CKD	No	184	(92.0)		
	Yes	16	(8.0)		

Table II: Sub analysis level of depression by BDI score (n=200)

BDI Score	Level of depression	n (%)
0-10	Normal	145 (72.5)
11-20	Mild	40 (20.0)
21-30	Moderate	11(5.5)
31-60	Severe	4 (2.0)

Table IV shows the results of multiple linear regression analysis of factors associated with stigma score among respondents. At the multivariable level, age and HIV status of the respondents significantly associated with TB stigma score. Every increase of age, the stigma score will decrease by 0.38 (95% CI -0.52, -0.23, P< 0.001) when HIV was adjusted. A person with HIV had stigma score higher than a person without HIV for 14.42 (95% CI 4.77, 24.07, P=0.004) when age was adjusted.

In term of relationship between stigma and depression score, there was a significant moderate, positive correlation between stigma and depression (r = 0.345, p<0.001) (Table V).

Table III: Factors associated with Stigma Score in univariate analysis (n=200)

Variables		Crude B	(95%	CI)	P-Value#
Age		-0.885	(-1.21,	-0.56)	<0.001
Gender	Male	1			
	Female	0.004	(-0.006,	0.014)	0.41
Race	Malay	1			
	Non-Malay	2.09	(-0.45,	4.63)	0.11
Marital Status	Married	1			
	Single	-4.32	(-6.46,	2.17)	0.001
	Divorced	-4.20	(-7.78,	0.62)	0.022
Employment	Yes	1			
	No	2.07	(0.16,	3.98)	0.034
Income	More than RM3k	1			
	Less than RM3k	-2.12	(-524,	1.00)	0.18
Education	Primary / No school	-4.20	(-7.16,	1.25)	0.006*
	Secondary	-2.14	(-4.61,	0.33)	0.09*
	Tertiary	1			
TB Contact	Yes	1			
	No	-0.23	(-2.59,	2.13)	0.85
Types of TB	Extra PTB	1			
	PTB	-0.78	(-2.80,	1.25)	0.45
Phase of TB treatment	Maintenance	1			
	Intensive	-1.12	(-3.03,	0.80)	0.25
HIV	No	1			
	Yes	6.13	(2.47,	9.80)	0.001
DM	No	1			
	Yes	-1.58	(-3.81,	0.64)	0.16
COPD	No	1			
	Yes	-3.45	(-8.06,	1.16)	0.14
Asthma	No	1			
	Yes	-8.88	(-18.47,	0.70)	0.07
CKD	No	1			
	Yes	-2.90	(-6.42,	0.62)	0.11

**ANOVA*
#Simple Linear Regression

Table IV: Factors associated with Stigma Score in multivariate analysis (n=200)

Variables	Crude B[c]	(95%	CI)	p-value [a]	Adj. B [d]	(95%	CI)	t-stat	p-value [b]
Age	-0.09	(-1.21,	-0.56)	<0.001	-0.38	(-0.52	-0.23)	-5.12	<0.001
No HIV	1								
HIV	6.13	(2.47,	9.80)	0.001	14.42	(4.77,	24.07)	2.95	0.004

[a] Simple Linear Regression [b] Multiple Linear Regression Constant = 39.03
[c] Crude Regression Coefficient [d] Adjusted Regression Coefficient = 15.5%
Coefficient

(The model reasonably fits well. Model assumptions are met. No interaction between independent variables and no multicollinearity problem. Variables in final model were selected via forward, backward, and stepwise selection)

Table V: Correlation between Stigma and Depression

Variable	Depression Score (%)	p-value*
Stigma Score (%)	0.345	<0.001

** Spearman's rho*

DISCUSSIONS

This paper focuses on measuring tuberculosis stigma from the perspective of patients, the associated factors, and its relationship with depression. To our knowledge, this research is the first in Malaysia to measure tuberculosis stigma quantitatively using the TB-related Stigma Scale, an instrument with good reliability and validity. Our study shows that the mean score of TB stigma is 13.3, which is relatively lower as compared with the standardized mean stigma score given as 27.6.[30] Based on previous studies conducted using a similar scale in other countries, our mean stigma score is also comparatively lower to those reported in Thailand, Kenya, Taiwan, Cambodia with the mean scores of 19.8, 20.7, 24.6 and 25.1 respectively. [27,33 - 35] However, our study finding was similar with few studies conducted in Sudan, Nicaragua and Turkey which demonstrated low level of tuberculosis stigma.[36-38]

These variations of TB related stigma could be attributed to many factors such as the difference in stigma measurement tools, study areas, sample sizes and participant characteristics. TB stigma is considered a complex concept because it is not easily assessed and thus, different methodological approaches for assessing TB stigma resulted in the slight variation in the product.[38] Considerable geographic variability also exists in the perceived prevalence of TB stigma, with 27% to 80% of individuals at risk reporting that TB is stigmatized in their communities.[39-41]

The other considerations may include the diversity of sociocultural, religious belief and health support system that may differ across communities and continents. A systematic review of 83 studies suggests that TB has different meanings for different ethnic and cultural groups based on the social context.[42] Cultural variation exists across the 35 countries with respect to the knowledge of TB related to the causes and transmission routes, as well as attitude and health responses, making the magnitude of TB related stigma also vary.[42]

In Malaysia, the reason that the stigma level is low as compared to other countries could be due to the fact that the overall satisfaction of patients in the quality of health care offered is good.[26] Also, all TB patients are given access to specialized TB clinic with the availability of dedicated paramedics and medical practitioners for counselling and management; and the TB medications are supplied for free. In addition, generally excellent rapport was established between the patients and health care providers during their treatment period, and this provides extra social support and creates a low-stigma environment. Another reason might be due to the fact that the diagnosis of TB in the Malaysian community is becoming more

acceptable, and hence, the patient felt less threatened by the diagnosis.[43] These factors might contribute to reduce the stigma experienced by TB patients. Nonetheless, these data should be interpreted with caution due to the restricted locality of the study in Kedah and the small sample size.

Our findings also showed that the age, marital status, education, employment, and HIV of patients were significant associated factors in the stigma experienced by tuberculosis patients. TB stigma is felt more strongly in certain subpopulations, including people with lower education levels and higher age.[18,33,38,42] Our study showed quite opposite results. Increasing age was demonstrated to be a protective factor for stigmatization in our study, which was also portrayed by Eldahshan et al.[44]

In terms of marital status, our findings were also consistent with Eldahshan et al; in which TB stigma was more prevalent in married patients.[44] This might be due to the fact that they have more relationship ties to be considered.[17] There are several other studies that have demonstrated contradicting results including XYin and Mbuthia et al, which showed that marital status is not significant in determining the level of stigma.[34,45]

Those patients who were unemployed were also at higher risk of higher stigma level, according to our study. However, this finding is inconsistent in several other research which revealed that employment is insignificant in determining TB stigma.[44,46,47] TB infection may cause a major impact to marginalized people with little social capital or those unemployed and this may further push them into poverty. This is because getting ill with TB may affect their ability to continue their work and earn money. In some countries, the treatment added to the financial burden.[17]

Other than that, as shown in many previous studies, our result disclosed that TB co- infection with HIV carries a significant indicator for higher stigma level.[16,20,33] This is due to the synergistic effect of both comorbid; as HIV itself is a key driver of high burden of stigma.[34] Our research also shows a similar finding and thus, the stigma reducing intervention needs to be concentrated more on this cohort of patients.

Our study showed that 27.5% of TB patients were depressed, with the majority of them categorized into mild severity, followed by moderate and severe depression. In addition, our study also demonstrates that patient related TB stigma has a significant, moderate positive correlation with the degree of depression. Tuberculosis patients with higher level of stigma were prone to develop severe depression as evidenced by multiple studies.[5,23,27] Among the contributing factors is due to the unduly fears and stress secondary to the misconception of tuberculosis which gives an impact to mental health.[5] It was also presumed that TB patients are considered as contagious in the society, which subsequently leads to stigma, discrimination, social isolation, and dismissal, and may predispose them to a greater risk of depression. [27]

The co-existing TB and depression has been implicated in poor treatment adherence and greater mortality.[4,5,48] Both conditions, when present concurrently can also lead to increased risk of comorbidities, more suffering and higher treatment cost expenditure.[49] Therefore, it is very crucial to integrate mental healthcare and the assessment of patient- previewed stigma in the care of tuberculosis patients, especially those with concomitant HIV infection and those in the younger age group.

The strength of this study lies in the fact that this is the first Malaysian study addressing stigma level quantitatively among TB patients. It is particularly important as the World Health Organization in its "End TB policy by 2035" is aiming to eradicate stigma in order to reach for millions of missing people who develop TB and go without care and support.[50] Therefore, the data retrieved from this study might be beneficial in planning and developing the strategy in combating TB, particularly in the arm of stigma related intervention.

Our results should be interpreted with caution considering several limitations. Firstly, this study generally focuses on TB population and not the community at large, thus, we could only capture the affected individual's self-experience related to TB, but not the view of the general community. Secondly, we only used the

quantitative method in assessing the stigma level in our study whereby the comprehensive assessment including qualitative analyses was not included. Finally, this study was carried out in Kedah, which is in the north Peninsular of Malaysia. The results may represent regions in the peninsular which have similar condition and culture but not generalizable to East Malaysia. Future studies should include an expanded population, mixed assessment methods, additional risk factors and different localities.

CONCLUSION

The mean score of tuberculosis related stigma in our research was not as high as we had initially postulated. Younger age, marital status, higher education, unemployment, and HIV co-infection were significantly associated with the stigma experienced. Patients' perspective stigma was also found to have a positive and moderate correlation with depression. Thus, the intervention to reduce stigma among TB patients may be helpful as it may reduce the depression level.

CONFLICT OF INTEREST

We declared no conflict of interest.

ACKNOWLEDGEMENTS

We acknowledged Pusat Pengajian Sains Perubatan Universiti Sains Malaysia (USM) for the Geran Penerbitan Sarjana Perubatan (GPSP) in funding the research.

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