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Tuberculosis and AIDS stigma among patients who delay seeking care for TB symptoms

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Summary

Background—Delay in presentation to a health facility is an important concern for TB control. The effect of stigma on delay in seeking care for TB symptoms is not well studied, especially in the context of the HIV co-epidemic.

Objective—To estimate the association of TB and AIDS stigma on delay in seeking care for TB symptoms.

Setting/Design—For 480 newly diagnosed patients with TB, time from first TB symptom to the first visit to a qualified provider was calculated. Stigma scales were administered to each patient to obtain a stigma score.

Results—Among men, those with higher TB stigma had a small increase in delay times, while women had a small decrease in delay. Among patients presenting with hemoptysis, higher TB stigma was associated with a small increase in delay, while among patients presenting with fever or extrapulmonary symptoms only, higher TB and AIDS stigma resulted in shorter delay times.

Conclusion—In a population with a relatively short median delay (26 days), the impact of TB and AIDS stigma translates into a minimal change in delay time. This suggests that stigma does not have a clinically relevant effect on TB patient delay in southern Thailand.

Keywords

Tuberculosis; Patient delay; Stigma

Introduction

From its introduction in 1994, DOTS has been the backbone of tuberculosis (TB) control around the world. With its focus on passive case detection, availability of diagnostic techniques, and directly observed therapy to minimize drug resistant TB, DOTS has been criticized as a treatment guideline and biomedical strategy that does not account for social factors related to TB control rather than a comprehensive control plan [1, 2]. Delay in presentation to a health facility is an important concern as it contributes to delays in initiating TB treatment. This can result in greater morbidity and mortality for the patient and increased transmission of *Mycobacterium tuberculosis* in the community [3-6].

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There is a large body of literature on factors associated with delay in seeking care for TB symptoms. These can be broadly grouped into access to care, personal characteristics, socioeconomic, clinical, TB knowledge or beliefs, and social support or psychosocial factors [7]. One psychosocial factor of interest is health-related stigma, often defined as a social process "characterized by exclusion, rejection, blame, or devaluation resulting from experience or reasonable anticipation of an adverse social judgment" because of a particular health condition [8]. Some studies have suggested that TB stigma could lead to delays in patients seeking appropriate medical care [9-11]. Others note that AIDS stigma and fears of being labeled as an AIDS patient could deter TB patients from seeking care because of the belief that someone with TB also has AIDS [12, 13].

Seven studies of delay among patients with TB or cough have included some measurement of stigma as a covariate. In six of these, stigma was not associated with patient delay in seeking care for TB symptoms [13-18], including one specifically assessing the relationship between TB stigma and delay using a modified stigma scale initially developed for AIDS and cancer. A multi-country study by the World Health Organization (WHO) in the eastern Mediterranean region reported that increased stigma was associated with decreased patient delay in Somalia [19]. No studies, however, have assessed the effect of both TB and AIDS stigma on TB patient delay using quantitative stigma scales.

Using formally developed stigma scales [20], this study investigated whether higher TB or AIDS stigma was associated with longer delays in seeking care for TB symptoms in southern Thailand.

Study Population and Methods

Study participants and data collection

Adults (>17 yrs) with newly diagnosed TB between August 2005 and July 2006 were enrolled from the regional TB center and seven hospital-based TB clinics in southern Thailand. Patients were not eligible if they had been receiving TB treatment for more than one month. Information on demographics, socioeconomic status, access to the first qualified health provider, TB knowledge, and TB symptoms were collected by trained interviewers using a standardized questionnaire. Patients were referred for HIV counseling and testing if their status was unknown or if they had tested negative more than six months prior to enrollment. An HIV test was not required for participation. Four stigma scales were administered to all participants: TB stigma from the community perspective (11 items) and patient perspective (12 items) and AIDS stigma from the community perspective (11 items) and patient perspective (10 items) [20]. Items were scored using a Likert scale with four levels: strongly disagree (0), disagree (1), agree (2), and strongly agree (3), with higher scores indicating higher stigma. Responses were summed for each scale to create stigma scores to be used in analysis. Stigma scores were standardized by dividing the summed score by the number of items in the scale, resulting in a possible range of 0 to 3. These item-adjusted scores were used to compare scores between scales.

Patient delay, defined as the time between onset of TB-related symptoms and the first visit to a qualified provider (private or public health clinic or hospital), was the outcome of interest. Health services delay, defined as the time between first presentation to a provider and diagnosis of TB, was not considered in this analysis because stigma would not be expected to affect clinical decisions or diagnostic processes. Upon enrollment in the study, patients were asked to recall the duration of their symptoms and when the first visit to a qualified provider occurred. Delay was calculated as the number of days between these two points. Patients who were asymptomatic were excluded from the analysis. The delay distribution was normalized using the $\log_{10}$ transformation to satisfy regression assumptions.

Analysis

Stigma scores and log-transformed delay were modeled as continuous variables using multivariable linear regression (SAS 9.1, PROC GENMOD with identity link and normal distribution). Four analyses were performed using each stigma score as the exposure of interest. Potential confounders were included in the model based on substantive knowledge and with the aid of directed acyclic graphs [21, 22]. These covariates included age, gender, religion, education, income, number of children and adults in the household, availability of a friend for travel to the health provider, travel time to the first qualified provider, mode of travel, TB knowledge (cause, transmission, and TB/HIV), prior testing for AIDS, HIV status, and TB symptoms. We considered interactions between stigma and gender, HIV status, and TB symptoms because it has been suggested that stigma adversely affects women [23] and that AIDS-related factors may play an important role in both stigma and delay [12, 13]. Interactions were assessed individually using interaction terms in the fully adjusted model. Interactions with $p \leq 0.20$ in at least one model were used in all four models. Regression results are presented as mean differences in log-transformed delay. Anti-log transformation of the parameter estimates requires complex bias-correction. However, anti-log transformation of the confidence limits provides an upper and lower bound for the relative change in delay on the day scale, rather than the log-day scale, which aids in the interpretation of the results.

Ethics approval

This study was approved by the Institutional Review Boards of the University of North Carolina and the Prince of Songkla University. Written informed consent was obtained from all patients.

Results

Participant characteristics

Fourteen asymptomatic patients (3%) were excluded from the analysis. An additional 34 (7%) patients were excluded due to improbable calculations of delay (32 with delay <0 days, two with delay >600 days). The final sample size was 432 patients. There was very little difference in exposure and covariate distributions among patients who were included and those excluded from the analysis, with the exception of mode of transportation (Table 1).

Nearly all patients (97%) knew that TB was curable. Patients primarily attributed their TB to smoking or drinking (34%), followed by infection from someone else (18%) or having a weak body (17%). While many reported non-infectious causes, transmission via eating, drinking, coughing, or sneezing was also reported. Most patients were aware of the link between TB and HIV.

Most patients experienced cough, with or without hemoptysis (76%). Upon diagnosis of TB, 67 (17%) patients were co-infected with HIV and knew their serostatus. Of the 314 patients referred for HIV testing, 235 (75%) accepted and 19 new infections were identified for an overall HIV prevalence of 20%.

Stigma and delay

Stigma scores could not be calculated for 13 (3%) patients due to incomplete item responses on the TB stigma from the community perspective scale and 16 patients (4%) for each of the remaining scales. All stigma scores had an approximately normal distribution and mean item-adjusted scores ranged from 1.65 to 1.97 (Table 1).

Delay was highly skewed and ranged from 1 to 365 days (Figure 1). Median delay was 26 days with noticeable digit preference. Log^{10} transformation effectively normalized the delay distribution. Within categories of covariates, median delay times ranged from 14 days among

those who presented with fever and/or extrapulmonary disease only, to 30 days among those who were HIV co-infected and those who presented with hemoptysis. The median delay time among men was one week longer than among women (28 vs. 21.5 days).

Adjusted results for the effect of stigma on delay are reported in Table 2 as the mean difference in log-transformed delay per unit increase in the summed stigma score. Results are reported for all TB patients and then stratified by gender and presenting symptoms. Among all patients with TB, stigma had no effect on delay with mean differences nearly equal to zero. Among men, a one unit increase in TB stigma from the community perspective was associated with a 0.012 (95% CI: -0.001, 0.025) increase in log-delay. Similar results were observed for TB stigma from the patient perspective. AIDS stigma had no effect on delay times among men. The opposite was observed among women, where those reporting higher TB stigma had a *decrease* in log-delay. AIDS stigma from the community perspective was also associated with a 0.015 (95% CI: -0.032, 0.002) *decrease* in log-delay among women.

When the effect of stigma on delay was stratified by presenting symptoms, there was no association between stigma and delay among patients presenting with cough. Patients with hemoptysis, however, had a 0.022 (95% CI: 0.001, 0.043) increase in log-delay per unit increase in TB stigma from the community perspective and a 0.035 (95% CI: 0.011, 0.060) increase for TB stigma from the patient perspective. AIDS stigma from the community perspective had a slightly smaller association. Among patients with fever or extrapulmonary symptoms only, both TB stigma scales had an inverse relationship with delay. This also occurred for AIDS stigma from the community perspective where patients had a 0.034 (95% CI: -0.069, 0.002) decrease in log-delay per unit increase in stigma.

Similar results were observed when delay was calculated as the time from first cough to the first visit to a qualified provider (Table 2).

Discussion

This is the first study to use formally developed TB and AIDS stigma scales to estimate the association between stigma and delay in seeking care for TB symptoms. Overall, we did not observe any association between TB or AIDS stigma and delay in seeking health care among individuals who were diagnosed with active TB. However, the estimates differed by gender, with men reporting higher TB stigma having longer delay times, and women who reported higher TB stigma having shorter delay times. Qualitative studies have reported that TB stigma adversely affects women more than men, primarily because of their sensitivity to social interactions [23]. In the context of seeking care for TB symptoms, our findings suggest women who report higher levels of TB stigma may seek care more quickly in an effort to relieve their symptoms and minimize any social consequences due to disease.

Among patients with hemoptysis, a symptom highly suggestive of TB, higher TB stigma was associated with increased delay time, while among patients with fever or extrapulmonary symptoms only, higher TB and AIDS stigma showed an inverse relationship with delay. It is interesting to find that among patients with atypical, non-cough symptoms, higher AIDS stigma from the community perspective was associated with shorter delay times. These patients may seek care in hopes that their symptoms are attributable to TB, rather than AIDS [12].

The actual impact of stigma on increasing or decreasing the delay time may not be large. The 95% confidence interval furthest from the null was for TB stigma from the patient perspective among those with fever or extrapulmonary disease. Anti-log transformation of this limit ($10^{-0.069} = 0.85$) indicates that the lower bound for any change in delay per unit increase in stigma is a 15% decrease. Given the median delay of 26 days in our study population, this corresponds to a maximum four day decrease in delay time. The impact of stigma would likely

be greater in populations where median delay times are much longer. Similarly, changes in stigma by more than one point could have a greater impact on delay. However, further analyses in the same population found that modifiable, socio-economic, TB knowledge, and HIV-related factors would only change summed stigma scores by a maximum of two points (Kipp et al., submitted).

Only one other study aimed to assess the effect of TB stigma on delay in seeking care for TB symptoms and did not find any association [18]. However, they modified a stigma scale previously developed for AIDS and cancer and found poor reliability among one of the sub-scales. Additionally, measurement of delay had important limitations. All patients received at least three months of treatment before enrollment and delay was only collected in four week intervals.

Other studies of delay used a measure of TB stigma as one of many predictor variables. These included informal measures of stigma such as feeling ostracized [14], a single question about whether TB is stigmatizing or not [15, 16], and multi-item measures of stigma that were categorized for analysis [13, 17]. Among these, only feeling ostracized was associated with increased delay [14]. A multi-country study of delay found that high stigma was associated with decreased delay in Somalia [19]. However, the scale that was used may not have been a valid measure of stigma because it included questions on the economic cost of illness and incorrect knowledge about the biologic effect on female reproductive outcomes and breastfeeding. While it is often suggested that poor TB knowledge causes higher stigma [24, 25], the evidence for this is not conclusive, with many studies showing no relationship between TB knowledge and stigma [26-28]. Therefore, poor TB knowledge should not be confused with, or used to assess, TB stigma.

Some limitations of our study should be acknowledged. Stigma was assessed only after patients presented at the TB clinics, concurrently with delay time calculation. The levels of stigma observed may not accurately capture the level of stigma near the time of symptom onset if stigma changes over time. Additionally, selection bias may have occurred because we only enrolled patients who presented at TB clinics. We expect this bias to be minimal. In order for our results to be biased towards the null, the effect of stigma would have to be many times stronger among those who never presented, which seems unlikely. And because our results are already small in magnitude, bias away from the null is unlikely. It is also possible that some recall error occurred. Finally, information on smoking was not collected in this study. While smoking is thought to be a cause of delay because smokers may mistakenly attribute their cough to smoking [29, 30], we do not expect this to bias our findings because smoking is unlikely to be associated with TB or AIDS stigma.

Conclusions

This was the first study to estimate the association of both TB and AIDS stigma on delay in seeking care for TB symptoms using formally developed stigma scales. Among all patients, no effect of stigma on delay time was observed. Stigma did have differential results within gender and presenting symptoms, likely contributing to the overall null effect. Nevertheless, in this population with a median delay of 26 days, the impact of stigma translates into a minimal change in delay time. This suggests that stigma may not have a clinically important effect on TB patient delay in southern Thailand.

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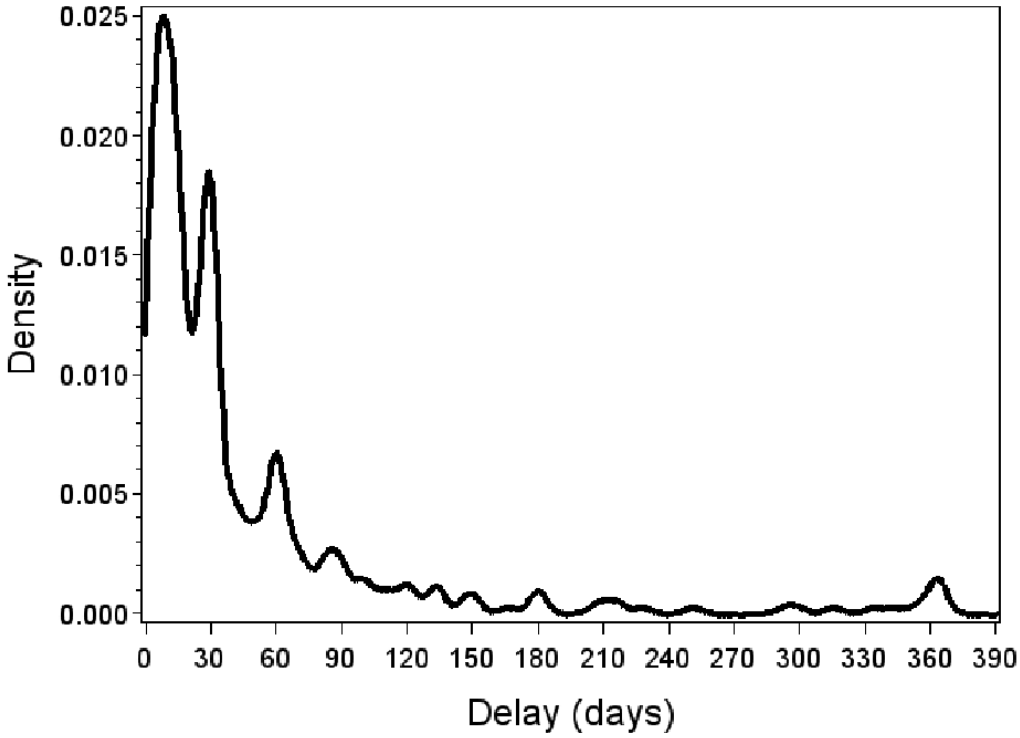

Figure 1.
Kernel-smoothed distribution of untransformed delay time.

Table 1

Distribution of patient characteristics, by inclusion status.

Continuous characteristics		**Included (n=432)**	**Excluded (n=48)**
TB stigma (Item-adjusted score)	Community perspective (mean, SD)	1.67 (0.45)	1.73 (0.41)
	Patient perspective (mean, SD)	1.65 (0.37)	1.70 (0.36)
AIDS stigma (Item-adjusted score)	Community perspective (mean, SD)	1.69 (0.47)	1.71 (0.47)
	Patient perspective (mean, SD)	1.97 (0.36)	2.00 (0.32)
Age	Age in years (median, range)	37 (18-79)	36 (18-73)
Income	Thousand Baht per month (median, range)	10 (0-90)	12 (0-52)
Household members	Children (<15 years old) (median, range)	1 (0-8)	1 (0-8)
	Adults (median, range)	3 (0-9)	3 (1-10)
Travel time to provider	Minutes to qualified provider (median, range)	20 (5-120)	25 (5-120)
Categorical characteristics		**N (%)**	**N (%)**
Gender	Male	284 (65.7)	33 (68.8)
	Female	148 (34.3)	15 (31.3)
Religion	Buddhist	286 (66.2)	33 (68.8)
	Muslim	144 (33.3)	15 (31.3)
Education	Less than primary school	143 (33.1)	17 (35.4)
	Completed primary	174 (40.3)	17 (35.4)
	Completed secondary	115 (26.6)	14 (29.2)
Friend to see doctor with	Yes	398 (92.1)	46 (95.8)
	No	34 (7.9)	2 (4.2)
Mode of transportation	Car/Motorcycle	338 (78.2)	35 (72.9)
	Bus	69 (16.0)	13 (27.1)
	Walk, Bicycle, Other	25 (5.8)	0 (0.0)
TB knowledge* (Cause)	Infected from family/others	78 (18.1)	9 (18.8)
	Work hard	64 (14.8)	7 (14.6)
	Smoking/drinking	146 (33.8)	16 (33.3)
	Heredity	18 (4.2)	2 (4.2)
	Weak body	75 (17.4)	7 (14.6)
	Eat or drink with patient	17 (3.9)	3 (6.3)
	Other	34 (7.9)	4 (8.3)
TB knowledge† (Transmission)	Eat/drink with patient	263 (60.9)	28 (58.3)
	Cough/sneeze	357 (82.6)	39 (81.3)
	Other (touch, sex, other)	113 (26.2)	15 (31.3)
TB knowledge (Cure)	Yes	418 (96.8)	45 (93.8)

Continuous characteristics		Included (n=432)	Excluded (n=48)
	No	14 (3.2)	3 (6.3)
TB knowledge† (TB/HIV)	TB increases chance of AIDS	221 (51.2)	21 (43.8)
	AIDS increases chance of TB	310 (71.8)	36 (75.0)
	Symptoms appear similar	305 (70.6)	34 (70.8)
Ever tested for AIDS	Yes	184 (42.6)	24 (50.0)
	No	248 (57.4)	24 (50.0)
HIV status‡	Negative	266 (61.6)	29 (60.4)
	New positive	19 (4.4)	2 (4.2)
	Known positive	67 (15.5)	6 (12.5)
	Refused test	80 (18.5)	11 (22.9)
TB symptoms§	Cough	221 (51.2)	17 (35.4)
	Hemoptysis	105 (24.3)	11 (22.9)
	Weight loss	55 (12.7)	4 (8.3)
	Fever and/or extrapulmonary only	51 (11.8)	2 (4.2)
	No symptoms	0 (0.0)	14 (29.2)

*Exclusive or

†non-exclusive categories

‡Known positives had previously tested positive for HIV infection; New positives identified when diagnosed with

§Cough and hemoptysis may include other symptoms; Weight loss excludes cough but may include other symptoms

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Table 2

Adjusted differences in mean, log-transformed delay times per one point increase in stigma score.

Stigma scale	Stratification	Any symptom delay MD (95% CI)*	Homog. p-value	Pulmonary delay† MD (95% CI)*
TB stigma (Community perspective)	All patients	0.004 (-0.007, 0.014)		0.005 (-0.007, 0.017)
TB stigma (Patient perspective)	All patients	0.003 (-0.009, 0.015)		0.003 (-0.010, 0.017)
AIDS stigma (Community perspective)	All patients	-0.003 (-0.013, 0.007)		-0.004 (-0.015, 0.008)
AIDS stigma (Patient perspective)	All patients	0.002 (-0.013, 0.016)		0.002 (-0.015, 0.018)
TB stigma (Community perspective)	Male	0.012 (-0.001, 0.025)	0.05	0.011 (-0.004, 0.026)
	Female	-0.009 (-0.026, 0.007)		-0.007 (-0.028, 0.014)
TB stigma (Patient perspective)	Male	0.011 (-0.004, 0.026)	0.12	0.010 (-0.007, 0.028)
	Female	-0.007 (-0.025, 0.010)		-0.007 (-0.028, 0.014)
AIDS stigma (Community perspective)	Male	0.004 (-0.009, 0.016)	0.08	0.002 (-0.012, 0.015)
	Female	-0.015 (-0.032, 0.002)		-0.015 (-0.035, 0.005)
AIDS stigma (Patient perspective)	Male	0.000 (-0.019, 0.018)	0.70	0.000 (-0.021, 0.020)
	Female	0.005 (-0.018, 0.029)		0.005 (-0.023, 0.032)
TB stigma (Community perspective)	Cough	-0.002 (-0.016, 0.012)	0.12	-0.003 (-0.017, 0.011)
	Hemoptysis	0.022 (0.001, 0.043)		0.024 (0.002, 0.045)
	Weight Loss	0.011 (-0.018, 0.039)		
	Fever or EPTB	-0.018 (-0.050, 0.014)		
TB stigma (Patient perspective)	Cough	-0.004 (-0.019, 0.011)	0.01	-0.005 (-0.021, 0.010)
	Hemoptysis	0.035 (0.011, 0.060)		0.028 (0.002, 0.053)
	Weight Loss	0.011 (-0.022, 0.044)		
	Fever or EPTB	-0.034 (-0.069, 0.002)		
AIDS stigma (Community perspective)	Cough	-0.008 (-0.022, 0.006)	0.15	-0.010 (-0.024, 0.004)
	Hemoptysis	0.015 (-0.004, 0.034)		0.010 (-0.010, 0.030)
	Weight Loss	-0.001 (-0.030, 0.027)		
	Fever or EPTB	-0.022 (-0.053, 0.009)		
AIDS stigma (Patient perspective)	Cough	-0.005 (-0.024, 0.014)	0.77	-0.003 (-0.022, 0.017)
	Hemoptysis	0.006 (-0.022, 0.035)		0.012 (-0.018, 0.042)
	Weight Loss	0.015 (-0.026, 0.056)		

Stigma scale	Stratification	Any symptom delay MD (95% CI)*	Homog. p-value	Pulmonary delay† MD (95% CI)*
	Fever or EPTB	0.014 (-0.037, 0.064)		

*Mean difference in $\log_{10}$ transformed days and 95% confidence interval

†Pulmonary delay calculated as the time from first cough to the first visit to a qualified provider