

# Stigma and Therapy Completion for Latent Tuberculosis among Haitian-origin Patients

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## ABSTRACT

*A prospective cohort study of LTBI treatment conducted within the Haitian population of South Florida investigated the predictive association between illness-related stigma among patients near the beginning of treatment and completion of preventive therapy. Factors associated with perceived stigma were also investigated. Ninety patients from Broward and Palm Beach counties were administered a questionnaire that included items related to illness history, perceptions and understanding of latent tuberculosis, and a 25-item stigma scale adapted from previously developed measures of tuberculosis-related stigma. Therapy completion was determined through a follow-up chart review. Data analyses compared patients who completed therapy with those who defaulted on a number of variables including perceived stigma. No association was found between perceived stigma or demographic characteristics and adherence to preventive therapy. Perceived stigma was associated with patient report of illness-related distress and was higher among patients who were lost to follow up. Some evidence suggested that stigma was higher among contacts of cases, patients with limited understanding of the condition, and patients who were more closely monitored during treatment. Case management should focus on patient-centered approaches to education and counseling about LTBI that address patient understanding of the condition and concerns about its physical and psychosocial effects.*

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## Introduction

This study investigated the predictive association between tuberculosis-related stigma and completion of preventive therapy for latent tuberculosis infection (LTBI). We tested the hypothesis that perceived stigma is negatively associated with adherence to LTBI treatment through a cohort study of latent TB patients of Haitian origin in Florida.

Completion rates for treatment of LTBI are consistently low across diverse populations (Bieberly & Ali, 2008; Hirsch-Moverman, Daftary, Franks, & Colson, 2008; Pina-Gutierrez, Ferrer-Traid, Arias, Sala-Farre, & Lopez-Sanmartin, 2008). A recent review of 78 studies found inconsistent associations between adherence and patient factors, clinic facilities, treatment characteristics and interventions to increase adherence (Hirsch-Moverman, et al., 2008). Researchers have suggested that social stigma may deter therapy completion among active tuberculosis patients (Macq, Solis, & Martinez, 2006), however we found no published studies that investigated stigma related to LTBI or the influence of patient-perceived stigma on completion of therapy.

In recent years public health attention to tuberculosis has been increasingly focused on immigrant groups that are disproportionately affected by the disease (Cain, Benoit, Winston, & MacKenzie, 2008). In South Florida, Haiti is the most common birth country (34.3%) among immigrants diagnosed

with TB (Talbot, Moore, McCray, & Binkin, 2000). Between 1993 and 1998, the case rate for active tuberculosis among Haitians living in the U.S. was 118.5 per 100,000 persons per year (Talbot, Moore, McCray, & Binkin (2000). Haitians make up only 2% of the state's population, but accounted for 15% of all active cases of TB during the time of our study. A retrospective chart and database review in 2000 of reported cases of LTBI in Haitians living in Florida found 38% of Haitians completed therapy, compared to a 60% completion rate for all others on therapy for LTBI (Lauzardo, Duncan, Szwed, Narita, & Hale, 2001).

The potential for TB-related stigma to be of concern within the Haitian population is noteworthy because of deeply-rooted prejudice and negative stereotypes of the Haitian population in American society (Farmer, 1992; Granich et al., 1998; Nachman, 1993). The legacy of labeling Haitians as a risk group for HIV/AIDS in the 1980s continues to negatively impact public perceptions as well as within-group perceptions of community attitudes towards this population (Coreil, Lauzardo, & Heurtelou, 2004; Stepick, 1998). Moreover, the resurgence of TB in recent years is associated with the AIDS epidemic. For these reasons, strong perceptions of stigma related to tuberculosis would be expected in this population.

## Study Population and Methods

The adherence cohort study conducted in Florida was part of a larger cultural epidemiologic study of stigma and tuberculosis in Haitian populations residing in Haiti and the USA. Patients were adults diagnosed with latent TB infection (PPD+ skin test, but x-ray negative and asymptomatic) who began preventive therapy through the Broward County Health Department or the Palm Beach County Health Department. In Florida, passive surveillance programs for TB are in place at public clinics that serve high-risk groups. Screening is offered to Haitians, other foreign born individuals, and others with risk factors for progressing to active disease who access all health department clinics and services, and approximately half of patients offered the treatment accept to begin therapy. First line recommended therapy is daily doses of isoniazid (INH) for a period of 9 months, if there are no contraindications.

Ethical oversight of the study was reviewed by the Institutional Review Boards of the University of South Florida, the University of Florida and the Florida Department of Health. All study participants gave informed consent to take part in the study.

A total of 90 patients were enrolled in the adherence study over a two year period (August 2005-July 2007), 63 from Broward County and 27 from Palm Beach County. Demographic characteristics of the sample are presented in Table 2. The primary outcome measure of adherence was completion of therapy. Adherence to the prescribed therapeutic regimen is monitored through monthly follow-up appointments where patients come in for a check-up and to receive a month's supply of medication. High risk patients, including children and HIV co-infected persons, are monitored through directly observed preventive therapy (DOPT). Follow-up data on treatment completion were extracted from patient records. Treatment adherence was measured by a dichotomous variable (complete vs. default) and analyzed in relation to several independent variables including stigma score, accurate understanding of the condition, perceived cause, reported distress, participation in DOPT, county of residence and socio-demographic variables.

Study variables were measured through an interviewer-administered questionnaire called the EMIC for Tuberculosis in Haitian Populations, adapted from a similar instrument developed for a multi-country study of tuberculosis and gender (Weiss et al., 2008). Development of the stigma scale began with a core set of items used in previous studies of stigma, including items related to internal perceptions and emotions, disclosure, external perceptions, external actions, and courtesy stigma

(effects on significant others). Based on local validation procedures and previous ethnographic research (Coreil, Lauzardo, & Heurtelou, 2004), two items were added to the scale related to patients feeling greater stigma because they were Haitian. Out of 34 items in the stigma scale, 9 were deleted because they showed weak correlations with the other items in the scale. The final scale (Table 1) consisted of 25 items with good internal consistency ( $\alpha = .87$ ). Coding of responses for the Stigma Scale ranges from 0-3 (0 for "no," 1 for "uncertain," 2 for "possibly," and 3 for "yes"). A composite stigma score is computed by adding scores for each item.

## Results

Overall level of perceived stigma was low, with a mean score of 25.1 for the total patient sample (maximum possible score of 100). The majority of patients responded "No" to most scale items, with the exception of items related to disclosure of one's diagnosis to others. Most participants (76-92%) indicated they would not discuss their condition with people outside the family (friends, neighbors, co-workers, church members, others), and about half (51%) would not discuss it with family members.

Of the 90 LTBI patients, 67 (74.4%) had chart-documented completion of therapy, 5 (5.5%) discontinued therapy because of medical advice, and 18 (20.0%) were categorized as "defaulters." Within the defaulter group, 5 had chart-documented voluntary withdrawal from therapy and 13 were considered "lost to follow-up" because they moved, could not be located, or no information was found in their charts regarding completion. No significant differences in therapy completion rates were found by county, socio-demographic characteristics, referral source, participation in DOPT, perceived cause or patient understanding of the condition. However, it is noteworthy that only the HIV co-infection group, all of which received DOPT, had 100% completion rates. No significant differences in mean stigma scores were found across therapy completion groups, categorized various ways. Likewise, no group differences were found when individual items in the stigma scale were analyzed separately.

Comparison of stigma scores between the treatment completion group and the defaulter group showed they were almost identical (24.9, 25.0). However when defaulters in the "moved or lost to follow-up" group (N = 6) were compared to other defaulters, significant differences in stigma scores were found. The "moved or lost to follow-up" group had a mean stigma score of 36.3 compared to a mean score of 21.6 for other defaulters ( $t = 2.65$ ,  $df = 21$ ,  $p = .015$ ).

**Table 1. Stigma Scale Items**

<i>Internal Perceptions and Emotions</i>	<ol style="list-style-type: none"><li>1. Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?</li><li>2. Have you ever been made to feel shamed or embarrassed because of this problem, or are you concerned that this might happen?</li></ol>
<i>Disclosure</i>	<ol style="list-style-type: none"><li>3. If possible, would you prefer to keep people from knowing about this problem?</li><li>4. Have you discussed or do you plan to discuss this problem with the person you consider closest to you, the one whom you usually feel you can talk to the most easily?</li><li>5. Have you discussed or do you plan to discuss this with neighbors?</li><li>6. Have you discussed or do you plan to discuss this with co-workers?</li></ol>
<i>External Perceptions</i>	<ol style="list-style-type: none"><li>7. Do your neighbors, colleagues or others in your community have less respect for you because of this problem, or do you think they would if they knew about it?</li><li>8. If they knew about it, would your neighbors, colleagues or others in your community think less of your family because of this problem?</li><li>9. Even if you don't (or didn't) have any other health problems, are people likely to think you do because of your TB germ/disease?</li><li>10. Are you worried that people will assume you have HIV?</li><li>11. Are you concerned that others will assume that you have the real TB disease?</li></ol>
<i>External Actions</i>	<ol style="list-style-type: none"><li>12. (If unmarried) Do you feel that even after your condition is cured, it might still make it difficult for you to marry? (If married) If you were unmarried, do you feel that this condition would have made it difficult for you to marry, even after it was cured?</li><li>13. Do you feel others have avoided or might avoid you because of this problem?</li><li>14. Would some people refuse to visit your home because of this condition even after you have been treated?</li><li>15. Have you been asked to stay away from work or social groups, or are you concerned that if people knew about it, that you might be asked to stay away even after treatment?</li><li>16. Might you decide on your own to stay away from work or social groups?</li><li>17. (If unmarried) If you were married, do you think your spouse might refuse sex with you because of the problem? (If married) Has your spouse refused sex or might refuse sex with you because of the problem?</li><li>18. (If unmarried) If you were married, do you feel that this condition would cause other problems in your marriage even after it was cured? (If married) Do you feel that even after it is cured, that this condition will create other problems in your marriage?</li><li>19. Now that you have this problem, do you think that your parents and siblings (or children)/parental family will provide or have provided adequate support?</li><li>20. Should your parents and siblings (or children)/parental family have done more to help you?</li></ol>
<i>Courtesy Stigma</i>	<ol style="list-style-type: none"><li>21. Might contact with you have any bad effects on others around you even after you have been treated?</li><li>22. (If patient has children) Do you feel that your condition might cause social problems for your children in the community? (If no children) If you had children, do you feel that your condition might cause social problems for them in the community?</li><li>23. Do you feel that this disease might make it more difficult for someone else in your family to marry?</li></ol>
<i>Haitian Identity</i>	<ol style="list-style-type: none"><li>24. Is it more embarrassing for you to have a TB-related condition <u>because you are Haitian</u> than it would be for other people in Florida?</li><li>25. Because you are Haitian will people think worse of you than others with the same TB condition?</li></ol>

**Table 2. Demographic Characteristics of Patients**

	N	%
Female	54	60.0
Palm Beach	27	30.0
Broward	63	70.0
Marital status:		
Single	31	33.3
Married/partnered	53	58.9
Divorced/widowed	6	6.7
Employment		
Full-time	46	51.1
Part-time	21	23.3
Unemployed	22	24.4
Religion		
Protestant	49	54.4
Catholic	27	30.0
Other	14	15.6
Literacy (yes)	79	87.8
Interview in Creole	86	95.6
Education		
8 yrs or less	18	20.0
9-11 years	20	22.2
12 years	19	21.1
> 12 years	23	25.5
Missing	10	11.1

Given that LTBI is a condition diagnosed in the absence of symptoms, it is not surprising that a majority of these patients (61.1%) reported that they experienced no forms of distress associated with the disease. When the no-distress patients were compared on stigma scores with those who reported some form of distress (physical, psychosocial, economic, medication side effects), a significantly lower mean stigma score was found (20.5 vs. 32.2,  $p = .003$ ).

Table 3 presents stigma scores in relation to referral source - that is, how a patient came to be diagnosed with LTBI, including contacts of active TB cases, HIV co-infection, work screening, school screening, refugee clinic, recent arrival and other sources. The highest mean stigma score was found among contacts of cases (31.2), and the lowest score was found among patients screened for employment (14.2). Stigma scores for patients in each category were compared to all others. Contacts of TB cases had higher stigma scores compared to all others (31.2 vs. 23.3), although this difference had borderline statistical significance ( $p = .059$ ).

Table 4 presents stigma scores by patients' understanding of their condition ("How would you

describe the condition for which you are being treated?"). About half the patients identified the "TB germ," the local term for LTBI in Haitian Creole. About 10% each identified the BCG vaccine, denied having any condition, or did not know. About 5% said they had TB disease. Patients who rejected the diagnosis of a medical condition had the highest mean stigma score (32.7), while those who correctly identified the TB germ had the lowest (22.7). Due to the small sample sizes and large variances across categories these differences were not statistically significant. It is noteworthy that patients who correctly identified the nature of their condition ("TB germ"), and those who identified the BCG vaccine, which is closely associated with "TB germ" in this population, there was markedly greater consistency in stigma scores, as reflected in lower variances.

Significant differences were found in patient stigma scores by county. The mean score for Broward County was significantly higher (29.3) than that for Palm Beach County (15.1) ( $t=5.2$ ,  $df = 84$ ,  $p < .0001$ ). Comparison of socio-demographic characteristics by county showed no differences in gender, education, income, or employment status, however patients from Palm Beach County on average had resided in the U.S. longer, were older, and proportionately more were widowed and Protestant. None of the latter socio-demographic differences were associated with stigma scores or adherence rate.

Closer examination of the defaulted patients was conducted based on their interviews and medical records, including demographic profile, illness history, responses to key questions, and narrative commentary provided to selected questions. It is interesting that all of the defaulters indicated that they intended to complete therapy when interviewed near the beginning of their treatment. Like other LTBI patients, they identified a variety of possible causes of their conditions, including in rank order diet, malnutrition, airborne exposure, constitutional weakness, water, physical exertion, humoral imbalance, BCG vaccine, germs/infection/contagion, sanitation, sexual contact, and a hard life, indicating that there is limited understanding of the ways in which people acquire latent TB, and the difference between latent and active TB.

## Discussion

Overall low levels of stigma were associated with latent TB infection in this population, however strong reluctance to disclose one's condition to others, including family members, was found.

**Table 3. Stigma Scores by Referral Source**

Referral source*	Frequency (%)	Stigma score	t-test vs. all others
Contact of case	20 (22.2)	31.2	.058
HIV co-infection	7 (7.8)	26.1	NS
Work screening	3 (3.3)	14.2	NS
School screening	3 (3.3)	30.0	NS
Refugee clinic	32 (3.3)	22.1	NS
Recent arrival	3 (3.3)	30.0	NS
Other referral	13 (14.4)	22.8	NS

\*Missing = 9

**Table 4. Stigma Scores by Patient Description of Condition**

LTBI description by patient	N (%)	Mean stigma	SD
TB germ	50 (55.6)	22.7	10.4
BCG vaccine	9 (10.0)	23.5	7.4
Reject diagnosis	9 (10.0)	32.7	21.8
Don't know/not told	10 (11.1)	26.7	23.8
TB disease	5 (5.6)	29.8	34.4
Other	7 (7.8)	28.1	24.4

Moreover, the findings do not support an association between patient-perceived stigma and completion of therapy for LTBI. Therapy completion was not associated with treatment facility, socio-demographic characteristics, referral source, participation in DOPT, perceived cause, or patient understanding of the condition. There was some evidence that completion was higher among HIV co-infected patients, but small sample size in the defaulter group limits interpretation of this finding.

The rates of therapy for LTBI completion found in this study were notably higher than what has been reported for other populations as well as in a previous statewide study of Florida's Haitian population (Lauzardo, Duncan, Szwed, Narita, & Hale, 2001).

Self-selection bias may have excluded patients most likely to default. Only patients who had begun therapy were included in the study, eliminating patients who refused treatment altogether. It is possible that patients who felt the most stigma related to their diagnosis, and were therefore more likely to default, were excluded from the study. Refusers often denied having any TB related condition, and did not want to have anything to do with a study of tuberculosis. In addition, study participants were recruited during the first month of treatment, and there is evidence that adherence during the first month of treatment is predictive of therapy completion (Menzies et al., 2005). However, therapy completion rates did not differ by county, despite

differences in refusal rate and stigma scores, as discussed further below.

Perceived stigma was higher among patients reporting some form of distress associated with LTBI, and among defaulters categorized as “lost to follow-up.” Contacts of cases and patients who misunderstood the nature of their diagnosis scored higher on stigma, although not statistically significant. Nevertheless, it is noteworthy that 44% of participants did not have a good understanding about the nature of the condition, including 11% who said they didn’t know what they had or were not told anything about the condition.

The higher stigma scores found among patients in Broward County compared to Palm Beach County may be attributed to at least two factors, the high refusal rate in Palm Beach County for participation in the study, and differences in county TB Programs. The refusal rate was 60% in Palm Beach County but only 15% in Broward County. It is possible that refusers felt greater stigma related to their diagnoses and therefore the Palm Beach participants were self-selected for lower stigma. Programmatic differences between counties also may have influenced differences in perceived stigma as well as participant recruitment. The main difference between counties is the organization of their Tuberculosis Programs. Broward County, for a variety of reasons had been able to garner more resources for their TB Program at the time of the study, and was therefore able to implement a higher level of supervision of LTBI patients, including more patients on DOT, than is the standard of care around the US. The more intense interaction with patients in Broward may have influenced the presence of higher stigma scores as well as the higher rate of participation in the study. This is consistent with other studies which report higher perceived stigma among patients treated in closely monitored TB treatment programs (Weiss, Auer, Somma, & Abouihia, 2006).

Research on the association between close supervision of therapy of LTBI and adherence is inconsistent. Some studies have found higher completion rates among patients receiving DOPT (White, Gournis, Kawamura, Menendez, & Tulsy, 2003), while others have found the reverse (Matelli et al., 2000). Our study did not show an association between level of patient monitoring and treatment adherence.

A limitation of the study was the small sample size of the defaulter patient group (N=18), which precluded multivariate analysis of results. Bivariate analyses suggested that differences in stigma scores within subgroups of defaulters, such as by referral source and understanding of the condition, warrant further investigation in relation to therapy

completion. Stigma reduction among patients is itself an important clinical goal, and our findings suggest that patients who report illness-related distress and patients who are lost to follow up perceive higher illness-related stigma. Results also highlight the need for effective patient counseling strategies to improve patient understanding of the causes and clinical aspects of latent TB infection, and to help patients make decisions about disclosure of the diagnosis to others (Ito, 2004). The findings underscore the importance of a patient-centered approach to stigma reduction, which focuses on influencing intrapersonal factors of the illness experience (Heijnders & Van Der Meij, 2006). In particular, early assessment of residential instability, patient comprehension and concerns about their diagnosis should be addressed in case management.

### Conclusion

No association was found between perceived stigma and adherence to preventive therapy for LTBI in this study of Haitian origin patients in South Florida. There was some evidence that closer clinical supervision of LTBI patients increased perceptions of stigma in patients, but this did not affect therapy completion. The findings are consistent with previous studies which have been unable to identify clear predictors of therapy for LTBI completion. Perceived stigma was associated with patient report of illness-related distress, and was higher among patients who were lost to follow up. The implications for clinical practice are that patient-centered approaches to education and counseling about LTBI should focus on patient understanding of the condition and concerns about its physical and psychosocial effects.

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