Insights Series #131

Blaming the Victim: Knowledge of Tuberculosis is Associated with Greater Stigma in Brazil

Mollie J. Cohen and Heather Ewing

with Marshall Eakin, Timothy Sterling, and Elizabeth J. Zechmeister

Vanderbilt University

mollie.j.cohen@vanderbilt.edu heather.m.ewing@vanderbilt.edu

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Key Findings:

- 16% of Brazilians believe that people with active TB should feel ashamed of their disease, and a similar proportion believe those with TB deserve to have the disease because of immoral behavior.
- Education is negatively associated with expressions of stigma toward individuals with TB.
- Knowledge of tuberculosis (TB) is fairly high in Brazil: over 60% of Brazilians are aware of latent TB infection.
- Those with higher levels of knowledge about TB are more likely to express stigmatizing attitudes towards persons with active tuberculosis.







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Tuberculosis (TB) surpassed HIV in 2015 as the world's leading cause of death from an infectious disease (World Health Organization 2015). For decades, TB has been among the top ten causes of mortality worldwide (World Health Organization 2018). While TB affects individuals around the globe, it disproportionately affects those in low and middle-income nations, and especially those living in major urban centers. In Brazil, where over 85% of the population lives in urban areas, including some of the largest cities in all of Latin America, TB is a significant public health challenge. In 2015, Brazil reported 84,000 new cases of TB, making it one of the globe's top 20 TB burden nations (Pelissari and Diaz-Quijano 2017).

In high-TB burden settings like Brazil, social stigma adversely affects infected individuals and, ironically, the health systems meant to care for them (Kelly 1999; Louw et al. 2012; Lee et al. 2017; Courtwright and Turner 2010). Patients who are stigmatized due to public knowledge of their TB diagnosis often become socially isolated, which can substantially reduce their quality of life and contribute to negative public health outcomes (Louw et al. 2012; Courtwright and Turner 2010). The adverse impact of stigma on patients can diminish the effectiveness of health systems themselves, as clinics struggle to retain patients who are confronting the consequences of social stigmatization. High patient attrition in turn increases the risk of developing drug resistant strains of the disease, increasing the severity of TB infection generally (Courtwright and Turner 2010; Kelly 1999; Lee et al. 2017).¹

Governments in high-TB burden societies have conducted informational campaigns as a means of increasing awareness of the disease while simultaneously minimizing stigmatized attitudes toward it. Yet, while studies have shown that stigmatization has negative effects on both patients and public health systems, few nationally representative studies have assessed the relationship between TB-specific knowledge on the part of the public and the prevalence of stigmatizing attitudes (see Rood et al. 2017).

This *Insights* report shows that, in a troubling reversal of expectations, greater levels of knowledge of TB symptoms are associated with a greater

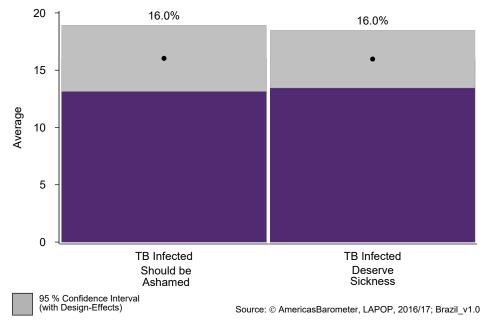


Figure 1: Percentage of Brazilians Reporting Stigmatized Beliefs toward Those with TB

likelihood of stigmatizing those with the disease, in effect, blaming the victims for their misfortune. $^{\rm 2}$

This *Insights* report examines predictors of TB stigmatizing attitudes: alongside more standard items, we consider the relevance of disease-specific knowledge on the part of the mass public. To accomplish these objectives, we use data from the 2016/17 AmericasBarometer survey in Brazil, which asked 750 individuals³ to respond "yes" or "no" to the following items in order to evaluate their agreement with stigmatized views of persons with TB:

TBS4B. People who have tuberculosis should feel ashamed of the disease.⁴

TBS4C. People who have tuberculosis deserve to be sick because of the way they live and their immoral behavior.

Figure 1 shows the percentage of respondents who answered each of these items affirmatively. About 16% of Brazilians express that those with

TB should be ashamed of their disease and an equal proportion agree that those with TB deserved to be sick.

Demographic and Socio-Economic Predictors of Stigmatizing Attitudes

Scholars of TB stigma find that it varies substantially across countries and across individuals (Adane et al. 2017; Craig et al. 2017; Rood et al. 2017). Although there are few studies on stigma of TB in Brazil, and to our knowledge no such studies that draw from a representative sample of any Latin American population, macro-level studies from other world regions suggest several individual-level factors that may be associated with TB stigma. Specifically, work from African nations shows that stigma toward those with TB is lower, on average, in countries where educational attainment is higher (Adane et al. 2017; Agho, Hall, and Ewald 2014; Mushtaq et al. 2011). Research from Pakistan and Nigeria finds that urban dwellers, living where TB is more prevalent, are more likely to stigmatize those with TB than their rural counterparts (Agho, Hall, and Ewald 2014; Mushtaq et al. 2011). Finally, several studies conclude that younger individuals are more likely to stigmatize those with TB than older persons (Adane et al. 2017; Agho, Hall, and Ewald 2014; Gilpin et al. 2011; Rood et al. 2017).

Below, we predict Brazilians' expression of stigmatizing attitudes toward those with TB using demographic and socio-economic variables. We also control for features of populations that are often associated with TB incidence. For example, in Brazil TB is geographically concentrated: the Southeastern region of the country accounts for 43.8% of Brazil's overall burden, and the Northeast region has the second most significant disease burden, at 27.3% (Pelissari and Diaz-Quijano 2017). Regardless of region of residence, darker skinned Brazilians are more likely to contract TB, as are those who live in areas where the mean income is low (Pelissari and Diaz-Quijano 2017).⁵ We therefore include as controls measures of

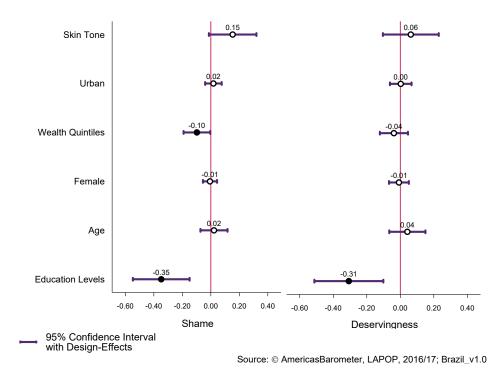


Figure 2: Maximal Effects of Demographic and Socio-economic Predictors on Expressing Stigma

education, age, skin tone,⁶ quintiles of wealth, and urban residence.⁷ We also control for respondent gender, and include regional dummy variables, which we do not show here to conserve space.⁸

Figure 2 presents the results of two logistic regression models estimating the effect of each independent variable on respondents' likelihood of responding affirmatively to each of the stigma measures, that is, expressing more stigmatized attitudes toward TB. Each dot signifies the estimated effect of a maximal increase in each independent variable (listed on the y-axis) on the likelihood of providing a positive (yes) response (vs. a negative response) to each dependent variable (on the x-axis). Horizontal bars represent 95 percent confidence intervals around these estimates. Hollow circles indicate that a given relationship is not statistically significant, and solid dots are associated with significant relationships. Dots to the right of the vertical line at zero represent positive relationships, while dots that fall to the left of the zero line represent negative relationships

between the independent and dependent variables.

We find that respondents with more education are significantly less likely to say that people with TB should feel ashamed and that they deserve to be ill. This finding, that expressions of stigmatized attitudes are lower among those with higher educational attainment, is consistent with previous studies. This result may indicate that those with more education are, in fact, more accepting of those with TB. On the other hand, those with more education may simply be more aware of, and thus more inclined to provide, the socially desirable response (in this case, one opposed to stigmatized expressions).

Both darker skin tone and material wealth are associated with a higher probability of expressing that those with TB should feel ashamed. Specifically, respondents with the darkest skin tone are fifteen percentage points more likely to respond that someone should be ashamed to have TB than respondents with the lightest skin tone, while those with the most material wealth are ten percentage points less likely than poorer Brazilians to report that someone with TB deserves to feel shame. We found no evidence significantly linking urban residence, gender, region, or age to either of these measures of stigma.

Knowledge of TB and Stigma

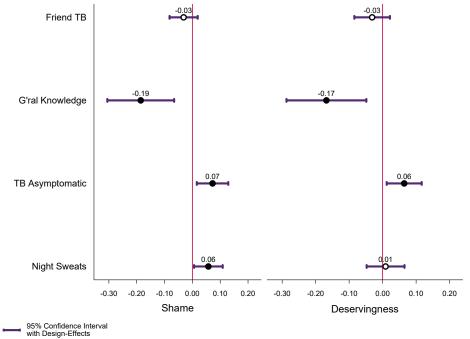
Health agencies often rely on public education as their central strategy for improving outcomes in the realm of infectious disease (Heijnders and Meij 2006). Increasing public knowledge of infectious disease is assumed to carry benefits including improved disease recognition, reduced delays in seeking treatment, and less stigmatization of the infected. Many education efforts aim to teach populations about the cause and treatment of a disease, and correct misconceptions that are understood to be responsible for stigmatization of the illness. Even as public health systems around the world invest substantial resources in educational interventions meant to increase knowledge and reduce stigma surrounding infectious disease, few evaluations of these programs' effects have been conducted (Heijnders and Meij 2006). At the same time, studies assessing whether disease-specific education decreases stigma towards those sick with other infectious diseases (e.g., HIV) have reached mixed conclusions (see e.g., Brown, Macintyre, and Trujillo 2003; Corrigan and Penn 1999).

We measure knowledge of TB using two variables: the ability to correctly identify that night sweats is a symptom of TB,⁹ and awareness of latent TB infection (LTBI)¹⁰; 48.8% of Brazilians identified night sweats as a symptom, and 60.6% correctly identified the existence of LTBI.

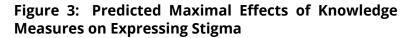
In addition to these key independent variables, we also controlled for two factors with the potential to confound the relationship between disease specific knowledge and stigma: respondents' general political knowledge (measured using interviewers' assessments) and self-reports of having a close friend or family member diagnosed with TB.¹¹ With respect to the former, those who know more about TB might simply be more knowledgeable, generally. Similarly, individuals who have close friends or family members with the disease may know more about symptoms, while expressing lower than average stigma. We therefore control for these factors in an attempt to isolate the effect of disease-specific knowledge.

Using logistic regression analysis, we estimate the relationship between these independent variables and the two dependent variables described above. We also control for all variables included in Figure 2, although we do not show the estimated coefficients to conserve space. As above, Figure 3 presents the estimated change in the likelihood of responding affirmatively to each stigmatizing attitude associated with a maximal change in each independent variable.

Higher levels of general knowledge are associated with lower stigma of individuals with TB, on average. As a respondent's general political knowledge increases from the minimum to the maximum rating, their likelihood of replying that a TB patient should feel ashamed decreases



Source: © AmericasBarometer, LAPOP; 2016/17; Brazil v1.0



by nineteen percentage points.¹² High knowledge individuals are also seventeen percentage points less likely to believe that individuals with TB deserve to be sick.

Importantly, those with high knowledge of TB (specifically, those who know TB can be asymptomatic and who recognize night sweats as a TB symptom) are more likely to express the stigmatizing belief that individuals with TB should be ashamed of their disease than those with lower levels of disease specific knowledge. Those who are aware that TB can be asymptomatic are seven percentage points more likely to express that those with TB should feel ashamed, and those who recognize night sweats as a symptom of the disease are six percentage points more likely to give this response.¹³ Similarly, individuals who correctly identified that TB can be asymptomatic are six percentage points more likely to say that individuals with TB should be ashamed than those who are unaware of latent infection.¹⁴ However, those who correctly identify night sweats as a symptom of TB are no more or less likely to believe that those infected with TB deserve to be ill. As a whole, these findings are somewhat startling, especially given the heavy reliance in public health programming on education as a mechanism for stigma reduction. We did not find any significant effect of having a close friend or family member with TB on respondents' likelihood to respond that someone with TB should feel ashamed of their illness, or that they deserve to be ill.

Discussion

Stigma involves the attachment of blame, negligence, or dirtiness to those infected with TB (Macq et al. 2005). Stigmatizing those infected with TB can result in the differential treatment of the sick. Further, these negative beliefs about disease victims can be internalized by individuals with TB, resulting in feelings of disgust, guilt and shame (Courtwright and Turner 2010) and, as well, decreasing the likelihood that infected individuals will seek out and complete courses of treatment. In short, not only does stigmatization of TB decrease individuals' quality of life but, as well, prevalent stigmatizing attitudes present a real challenge for improving public health.

To combat stigma and improve health outcomes, public health agencies around the world have implemented public information campaigns, with the expectation that increasing disease-specific knowledge will decrease stigma in the population and lead to improved treatment outcomes. While we cannot directly test the effect of information campaigns here,¹⁵ this study shows that more information does not translate directly into lower stigma. Indeed, we find that individuals with relatively more disease-specific knowledge are more likely to stigmatize those with TB than individuals who are unable to identify the existence of LTBI or specific TB symptoms.

We do not suggest that public health agencies stop informing the public about the symptoms and negative consequences of TB. Rather, this study points to a need for assessments of the potential for unintended consequences of public information campaigns. In particular, this finding speaks to a substantial body of research that assumes greater diseasespecific knowledge leads to less stigmatization in general. We do not find evidence consistent with this assumed, general relationship. Although we cannot speak specifically to the causal effect of knowledge on stigma, our work suggests that academics and policymakers should take care not to assume that specific knowledge always lowers stigmatizing attitudes toward the sick, disabled, or addicted. Perhaps our findings are specific to Brazil or to TB alone. Regardless, this work points to the need for future research to identify what kinds of messages might be most effective at minimizing stigma, and under what circumstances.

Notes

1. Reduced quality of life, isolation and lack of social support are often described as key factors negatively impacting TB patients and retention in care (Courtwright and Turner 2010; Sommerland et al. 2017). Stigmatizing beliefs held by health workers, who themselves frequently become ill with TB, have been linked to delayed treatment-seeking,

work absenteeism, and increased hospital costs. These challenges further complicate the delivery of care in overburdened health systems (Sommerland et al. 2017).

- 2. In line with these findings, recent work using pooled Demographic Health Survey (DHS) data from 15 studies in 13 countries concludes that TB stigma is positively correlated with knowledge of TB transmission (Rood et al. 2017).
- 3. Prior to being asked the stigma questions, respondents were randomly assigned into one of two conditions. Half (750) received the TB stigma questions; the other half received questions assessing stigma toward individuals infected with Zika.
- 4. Drawing from studies of stigmatized attitudes of those with HIV, the battery also included items assessing individuals' preferences for avoiding physical contact with TB-infected individuals, and avoiding them on public transportation. Studies from different countries use models for airborne disease transmission to show that people who use public transportation are at heightened risk for exposure to TB (Andrews, Morrow, and Wood 2013; Feske et al. 2011; Horna-Campos et al. 2007). Avoiding direct contact and avoiding contact on public transportation may thus reflect the rational avoidance of germs in addition to stigma. Because of this theoretical difference, we present here only measures that explicitly tap stigma. We note that results of identical logistic regression models for the dependent variables on physical contact yield results similar to those presented below. There may thus be an important set of links among disease specific knowledge, the rational avoidance of germs, and stigma.
- 5. Pelissari and Diaz-Quijano (2017) find that infection is more common among those that they code as having "black and brown", versus other, skin tones.
- 6. Interviewers recorded respondents' facial skin tone following the interview using an 11-point color scale, with darker skin coded with higher numbers (see e.g., Telles 2014).
- 7. LAPOP uses a series of questions about household belongings to generate a five-category measure of material wealth using urban and rural principal components analyses. For more details, see Córdova (2009). Urban is a dummy variable, coded as 1 if the respondent lives in an urban region, and 0 if in a rural area. The gender dummy variable takes the 1 value if the respondent is female. Age is divided by cohort, with respondents grouped into the following age categories: 16-25, 26-35, 36-45, 56-65, and 65+. All independent variables are recoded on a scale of 0 to 1.
- 8. Stigma is lower, on average, in the Southeast, South, and Northeastern regions of Brazil.

- 9. The study included four measures of respondents' knowledge of TB, including their awareness of latent TB and their recognition of three symptoms (coughing and chest pains; weight loss and night sweats; and stomach pains, which is not a symptom of TB). Scholars suggest that 30-70% of respondents should give correct answers to items for reliable knowledge scales (see e.g., Delli Carpini and Keeter 1993). The first and third symptom items were insufficiently discriminating by this metric: 79% and 71.6% of respondents gave the correct answer for each item, versus 48.8% for the night sweats item and 60% for knowledge of LTBI. When all four items are included in the model, the effect of night sweats is attenuated and no longer reaches standard thresholds of statistical significance. The positive and significant effect of knowledge of LTBI, in contrast, is consistently positive and significant.
- 10. **TB2.** "According to what you know, is it possible for a person to be infected with tuberculosis (TB) without feeling or appearing sick?" 5.74% of respondents reported that they did not know, and were coded as "0". Results are robust to excluding these "don't know" responses.
- 11. **CONOCIM** Using the scale presented below, please rate your perception of the level of political knowledge of the interviewee (1) Very High (2) High (3) Average (4) Low (5) Very Low. We recoded this variable so that higher values indicate higher levels of political knowledge. **TBS1** Has one of your friends, family members or someone you know well ever been diagnosed with TB?
- 12. This finding is consistent with past scholarship on the link between stigma and information; scholars have shown that education is associated with decreased stigma. These findings suggest a differentiable effect of general knowledge versus disease-specific knowledge, and add important nuance to the link between information and attitudes about disease.
- 13. Interviewers' assessments of respondent knowledge are correlated with TB specific knowledge at 0.10, with knowledge that TB can be asymptomatic at -0.02, and with level of education at 0.40. TB specific knowledge is correlated with education at 0.04 and with knowledge that TB can be asymptomatic at 0.05, and knowledge that TB can be asymptomatic is negatively correlated with education (-0.06). The direction of the results presented in Figure 3, although not the exact size of coefficients, is robust to sequentially including each of these knowledge variables in the model.
- 14. This positive relationship persists when the general knowledge variable is excluded from the model, suggesting that the positive finding is not due to high covariation across knowledge measures.

15. We cannot rule out the possibility that initially, stigma among those who eventually became more informed was even higher. That is, it may be the case that exposure to information about TB decreased stigma among those receiving the information. Because we cannot observe attitudes prior to treatment, we cannot know with certainty. Assessing the effect of information campaigns on TB stigma would require an experimental research design, which we leave to future research.

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Appendix

Variables	Shame	Deservingness
Education Levels	-0.82^{*}	-0.71^{*}
	(0.21)	(0.21)
Age (Cohort)	0.04	0.07
	(0.08)	(0.08)
Female	-0.05	-0.07
	(0.22)	(0.25)
Wealth Quintiles	-0.21^{*}	-0.08
	(0.10)	(0.09)
Urban	0.16	0.02
	(0.28)	(0.27)
Skin Tone	1.13^{*}	0.48
	(0.55)	(0.62)
Northeast	-0.61^{*}	-0.35
	(0.28)	(0.32)
Central-West	-0.41	-0.59
	(0.31)	(0.37)
Southeast	-0.92^{*}	-0.91^{*}
	(0.29)	(0.30)
South	-0.92^{*}	-0.70^{*}
	(0.39)	(0.33)
Constant	0.39	0.03
	(0.56)	(0.64)
Observations	762	751

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* indicates $p \leq .05$. Standard errors in parentheses.

Variables	Shame	Deservingness
Knows TB Asymptomatic	0.69^{*}	0.55^{*}
	(0.28)	(0.24)
Night Sweats	0.52^{*}	0.07
C	(0.24)	(0.23)
Knowledge–Interviewer	-0.41^{*}	-0.33^{*}
-	(0.13)	(0.12)
Family Member with TB	-0.30	-0.27
	(0.25)	(0.23)
Education Levels	-0.55^{*}	-0.43
	(0.23)	(0.23)
Age (Cohort)	0.04	0.07
	(0.08)	(0.09)
Female	-0.22	-0.18
	(0.24)	(0.25)
Wealth Quintiles	0.17	-0.05
	(0.10)	(0.09)
Urban	0.02	-0.10
	(0.31)	(0.32)
Skin Tone	0.94	0.37
	(0.57)	(0.63)
Northeast	-0.54	-0.33
	(0.31)	(0.32)
Central-West	-0.54	-0.70
	(0.33)	(0.38)
Southeast	-0.84^{*}	-0.89^{*}
	(0.31)	(0.31)
South	-0.90^{*}	-0.65
	(0.43)	(0.35)
Constant	0.58	0.33
	(0.69)	(0.73)
Observations	715	709

Table 2

* indicates $p \leq .05$. Standard errors in parentheses.

Dr. Mollie J. Cohen is a postdoctoral research fellow at LAPOP.

Heather Ewing is a Masters student in Public Health and Latin American Studies at Vanderbilt University.

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As a charter member of the American Association for Public Opinion Research (AAPOR) Transparency Initiative, LAPOP is committed to routine disclosure of our data collection and reporting processes. More information about the AmericasBarometer sample designs can be found at vanderbilt.edu/lapop/core-surveys.

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- vanderbilt.edu/lapop 🔇
 - @lapop_barometro 🕑
- @LatinAmericanPublicOpinionProject
 - lapop@vanderbilt.edu ₩
 - +1-615-322-4033
- 230 Appleton Place, PMB 505, Suite 304, Nashville, TN 37203, USA 💡