Published in final edited form as:
*J Health Care Poor Underserved*. 2012 May ; 23(2): 636–650. doi:10.1353/hpu.2012.0046.

# Anticipated tuberculosis Stigma among Health Professionals and Haitian Patients in South Florida

**Jeannine Coreil, PhD, MA**,
Department of Community and Family Health at the University of South Florida in Tampa.

**Michael Lauzardo, MD, MSc**, and
Southeast National Tuberculosis Center, Department of Medicine at the University of Florida in Gainesville.

**Maude Heurtelou, MS**
Educa Vision in Ft. Lauderdale.

## Abstract

This paper compares tuberculosis-related stigma perceptions of health professionals with that of local patient populations, and examines these in relation to other measures of anticipated distress. Comparison groups were service providers and Haitian American patients diagnosed with latent TB (LTBI). Providers consistently rated LTBI higher on anticipated stigma than patients both overall and for internal perceptions and emotions, external perceptions and actions, and Haitian identity. Health professionals were almost five times more likely than patients to report the possibility of other types of psychosocial distress. The findings are consistent with previous studies reporting a higher degree of perceived stigma among unaffected populations compared with people diagnosed with a medical condition. Results suggest that providers may overestimate the likelihood that patients with a stigmatized condition will experience negative consequences. This may negatively affect adherence to TB testing guidelines because of confidentiality concerns. The implications for achieving national TB elimination goals are discussed.

## Keywords

stigma; latent tuberculosis; health professionals; Haitian Americans; South Florida

Research on illness-related stigma has largely focused on affected people and the general population, with much less attention to health care providers.[1–3] Studies of medical and social service professionals have documented the persistence of negative perceptions and behavior towards people with mental illness, HIV/AIDS and leprosy.[4–9] However, few studies have addressed stigma perceptions of providers in relation to comparable measures of stigma perceptions in the populations they serve.[10] Additionally, a literature review found no studies of tuberculosis-related stigma among health professionals. The research reported here compared tuberculosis-related stigma among health care providers with that of locally served patient populations, and examined these stigma patterns in relation to other measures of anticipated distress related to the condition. Research on illness-related stigma has documented a range of consequences for affected people.[11–13] Most studies focus on the negative effects of stigma such as social exclusion and discrimination, while others highlight

---

Please address correspondence to Jeannine Coreil, PhD, Department of Community and Family Health, University of South Florida, 13201 Bruce B. Downs Blvd., Tampa, FL 33612; (813) 980-2265; jcoreil@health.usf.edu..

health benefits such as reduction in tobacco use and increased compliance with therapeutic regimens.[5,14–16]

In recent years researchers have differentiated various cognitive and behavioral dimensions of illness stigma, as well as distinctive social groups involved in stigmatization.[9,17–19] For example, studies offen make comparisons between "perceived" or "anticipated" stigma, and "enacted" stigma among affected and unaffected populations.[5,19] Comparisons across studies are complicated by variability in conceptualization, measurement, focal condition, and social group investigated.[2,4] However, one consistent finding across studies is the reporting of lower levels of perceived stigma among patients than among unaffected populations.[4,20–22] One explanation for this pattern is that affected people tend to minimize or deny the stigmatizing effects of the condition as a coping strategy, while the unaffected tend to focus on potential problems, such as difficulty finding a marriage partner.[22] A second view suggests that affected people have come to terms with living with the condition and therefore perceive it as less stigmatizing than those who have not been affected.[20] This study enabled examination of the problem within the broader context of other categories of distress associated with the condition in order to determine whether similar group differences hold for other psychosocial consequences as well. In addition, the study compared providers' expectations of negative consequences with those of newly diagnosed patients, who presumably have had little time to come to terms with their conditions.

Tuberculosis has a long been associated with negative societal attitudes because it primarily affects marginalized groups including the poor, malnourished, homeless, incarcerated, drug addicted, and (most recently) HIV-positive individuals.[23] Moreover, TB is feared as a contagious disease that poses a public health threat to the general public.[9] In recent years TB has become increasingly associated with foreign-born populations who already face discrimination related to immigration status.[24] In Florida, TB is disproportionately associated with the Haitian population, a group that has experienced AIDS-related and other forms of discrimination.[25–27] Thus one would expect a high degree of stigma associated with TB in this population, but whether such stigma extends to latent TB, which is asymptomatic, non-contagious and poses no immediate public health threat, raises important questions for this investigation.

The data reported here are part of a cross-national study of stigma and tuberculosis in Haitian populations that used the theory and methodology of cultural epidemiology,[28–31] an approach that integrates quantitative and qualitative measures of locally meaningful cultural categories. The theory behind this approach derives from cognitive anthropology and the *emic* (or, *insider*) perspective on illness representations. Shared norms for illness perceptions and behavior are theorized to exist within socially meaningful groups. Cultural epidemiology seeks to describe the distribution of such beliefs within defined populations, for purpose of cross-cultural and intra-cultural comparison. The insights gained from systematic group comparisons have theoretical significance, such as better understanding of stigma processes, as well as practical implications for the delivery of services. The methodology of cultural epidemiology has been applied in various settings and and to various health problems.[3,4,22,32] This paper aims to answer two related questions. First, how do expectations about TB-related stigma among health care providers compare with those of TB patients themselves? Second, are the observed patterns of group differences for stigma expectations similar to those for other forms of psychosocial distress such as social isolation, problems within the family, loss of income, sadness, and anxiety?

The focal condition of the study is latent tuberculosis infection (LTBI), which affects a large proportion of immigrants from TB endemic countries like Haiti. Because there are no physical symptoms associated with LTBI, most people are unaware of their condition until diagnosed through a variety of mechanisms, including investigation of contacts of active TB cases, routine employment or educational testing, immigration-related screening, and passive surveillance at public clinics serving high-risk groups. The recommended therapy for LTBI is daily doses of isoniazid (INH) for a period of nine months. Treatment is voluntary and only about half of Haitians living in Florida diagnosed with latent TB agree to begin therapy.[33]

The study of disease-related stigma in the Haitian American population is a sensitive issue because of the history of racism and prejudice experienced by the Haitian population in the U.S., even long before the advent of the AIDS pandemic.[26,27,34–36] In particular, public stereotypes and strong feelings persist from the labeling of Haitians as a risk group for HIV/AIDS in the 1980s.[25,34] Because of its association in recent years with HIV/AIDS as a common co-infection, TB has come to be viewed by many as a marker for HIV and is associated with increased social stigma and fear.[36]

## Methods

### Study design

The study design involved two phases. First, an ethnographic assessment was conducted to identify locally relevant sociomedical dimensions of TB among the subpopulations of interest. Second, a semi-structured instrument to measure TB-related stigma and perceived distress was developed and administered to the comparison groups.

### Ethical oversight

Ethical review of the study was conducted by Institutional Review Boards of the University of South Florida, the University of Florida and the Florida Department of Health. Written informed consent was documented for all study participants.

### Data collection–Phase I

Phase I data collection included participant observation in TB clinics, and in-depth interviews and focus group discussions with TB patients and health care providers. Study participants were recruited from tuberculosis clinics under the management of the two county health departments in Florida. A total of 100 hours of observation took place at five clinics in the study communities. Observers were members of the research team who had been trained to look for (1) arrangements or practices that affect confidentiality; (2) interaction between clinic staff and clients (e.g., customer-friendliness, respect, personal attention); (3) language use and communication (e.g., availability of Haitian Creole speakers or translators and Haitian Creole language documents); and (4) patient understanding of latent TB infection and the treatment regimen. Open-ended interviews were conducted with a total of 24 providers and 33 patients. Interview guides included open-ended questions on the most important health problems in the local community, individual and collective behavior related to stigmatized illnesses, explanatory models (i.e., perceived causes, symptoms, and treatment) of tuberculosis, and the impact of tuberculosis on affected people, including social stigma.

Analysis of observation and interview data from Phase I informed the development of quantitative measures incorporated into a questionnaire used in Phase II. Draff instruments were tested for validity and comprehension with four focus groups, including two groups of providers and two groups of patients. Participants carefully reviewed each item in the questionnaire and provided feedback on cultural appropriateness, understandability and need for probes and clarification, identification of potential problems items requiring special interviewer training, and assessment of whether the items adequately covered all important topics related to stigma and tuberculosis in the study population. Modifications were made to the instrument based on the focus group feedback, and the final version was pretested with three LTBI patients and three providers.

## Data collection–Phase II

The instrument used in this study to measure stigma was a 20-item interviewer-administered questionnaire adapted from a similar tool developed for a multi-country study of tuberculosis and gender.[32] The stigma index measured internal perceptions and emotions, external perceptions, external actions, disclosure, and stigma related to Haitian identity (Box 1). The items included in the instrument were evaluated for appropriateness and adapted for the study population as described above for Phase I. For example, because of the impact that co-infection with HIV has on stigma related to TB in the Haitian population, an item was included that addressed this issue. In addition, ethnographic data indicated that social stigma related to Haitian identity was a significant issue for this population,[28–29] so two items related to this concern were incorporated. Internal consistency of the index was assessed through inter-item correlations and found to be within the acceptable range (Chronbach alpha = .93 for the provider sample and .83 for the patient sample).

In the questionnaire administered to patients, interviewees responded to stigma questions in relation to their own experience or anticipated consequences, while the instrument administered to health care providers asked them to respond in relation to the following vignette of a fictive person with latent TB.

Marie Rose is a 40 year old woman who was born in Haiti but has been living in the United States since she was a child. She lives with her husband, their three children, and Marie Rose's 66 year old mother. Recently Marie Rose's mother was diagnosed with tuberculosis, and her doctor said that everyone in Marie Rose's family should be tested for TB. Marie Rose's skin test came back positive, but she has no symptoms of illness, —no cough, no fever, no sweats, and she feels fine. And the doctors said her chest x-ray is normal.

In addition to the stigma index, the questionnaire included a set of items related to patterns of distress experienced or anticipated by someone affected by latent TB. These included psychosocial consequences such as social isolation, problems within the family, loss of income, sadness, and anxiety. For each category of distress, study participants were asked to indicate whether someone diagnosed with LTBI might encounter the problem, and responses were coded as either Yes or No.

## Sample selection

The questionnaire was administered to a total of 43 health care providers and 90 patients diagnosed with LTBI, 63 from County A and 27 from County B. All providers were involved in the delivery of TB services and included doctors (9.5%), nurses (33.3%), social workers/case managers (30.9%), and others (26.2) (nursing assistants, respiratory therapists, program administrators with medical backgrounds). Providers were recruited from a convenience sample including health department TB service staff (56.1%), clinicians in private practice (31.7%) and hospital staff (12.2%). About two-thirds of providers were of Haitian descent. Patients were in the early stage of treatment, and included contacts of active TB cases (24.7%), referrals from refugee clinics (43.2) and other health department clinics (24.6%), and individuals diagnosed through work or school screening (7.4%).

## Data analysis

The data analysis strategy consisted of calculating mean scores on stigma measures for each group and testing for mean differences in both composite scores and for individual items using the *t* test. Associations between stigma scores and demographic factors were analyzed to rule out confounding factors in observed group differences. These analyses included tests of correlation (Pearson's r) between stigma scores and continuous demographic variables (age, education, income, years living in the U.S.) and tests of mean differences (t-test) on stigma scores between groups defined categorically (gender, religion, marital status). Differential rates of reporting other forms of psychosocial distress were calculated by comparing the proportion of providers reporting any form of distress with the proportion of patients reporting any form of distress, and calculating an odds ratio for the two proportions.

## Results

Results are presented in four sections. First, the demographic profiles of the comparison groups are presented to provide an overview of the sample characteristics. Second, stigma scores for providers and patients are compared to determine whether statistical differences exist between groups. Third, the proportion of patients and providers reporting any type of psychosocial distress associated with latent TB are compared. Fourth, potential confounding of group differences based on sample demographic characteristics is examined.

As one would expect, providers had a different sociodemographic profile from that of patients (Table 1). On average they were older, had a higher proportion of females, had more years of school and income, and had been living the U.S. longer. Among providers there was a higher proportion of Catholics than Protestants, but among patients this was reversed, and there were more single participants among patients and more divorced people among providers.

Health care providers had a mean composite stigma score of 26.6, significantly higher than the mean composite score of patients, which was 17.1 (Table 2). On individual items, providers had significantly higher scores than patients on most of the items, and on no items did patients score significantly higher than providers. Providers scored higher on stigma related to internal perceptions (think less of self, feel ashamed, others have less respect); association of LTBI with other health problems (assume other health problems, assume have TB disease, assume have HIV); external actions (problems at work, others avoid); and Haitian identity (more embarrassing to have LTBI because one is Haitian and others think worse of someone because of being Haitian). While providers reported higher stigma related to hiding the problem from others in general, no group differences were found on likelihood of disclosure to specific categories of others, including family members, friends, neighbors, church members and co-workers. Both providers and patients assigned the highest stigma scores in the index to these disclosure items.

For both providers and patients, the most frequently reported form of anticipated psychosocial distress was “sadness, worry, or stress,” and providers also frequently identified social stigma as a potential negative consequence (Table 3). Again, providers report significantly more anticipated distress than do patients. Providers were almost five times more likely than patients to identify one or more form of psychosocial distress as probable for someone with LTBI (OR 5 4.97, 95% CI (3.2, 7.6).

To rule out the possibility that demographic differences in the comparison groups accounted for the observed differences in stigma scores, bivariate analyses were conducted of the association between composite stigma score and each of the demographic factors reported on Table 1. No associations were found between stigma and age, gender, education, income, marital status and years of residence in the U.S. Regarding religion, among providers no differences in stigma between Protestant and Catholic providers were found. Protestant providers had a higher but non-significant mean stigma score compared to Catholics.

Among patients, Catholics scored significantly higher on stigma than Protestants ($t=2.47$, $df=74$, $p<.05$). So, the influence of religion was inconsistent across the two groups and therefore suggests that had the groups been matched on religion, the results would not have differed.

## Discussion

### Study limitations

The limitations of the study include the use of a convenience sample of providers and the heterogeneity of the provider sample. A randomly selected sample of providers and one that allowed comparison of different types of providers would have strengthened the study and allowed for a more refined analysis.

Previous studies have reported a higher degree of perceived stigma related to a medical condition among community populations compared with people diagnosed with the condition.[4,20–22] The findings of this study of TB-related stigma among health care providers are consistent with a general trend that perceived stigma appears to be higher among unaffected populations than among those who are living with the condition. The design allowed the comparison of anticipated stigma among health care providers with the level of stigma expected by diagnosed patients from the same community. Although the degree of perceived stigma was low overall for both populations, as would be expected for an asymptomatic condition that has no risk of contagion, it is interesting that providers consistently rated the condition higher on anticipated stigma than patients for questions related to internal perceptions and emotions, external perceptions and actions, and items related to Haitian identity. Only on items related to disclosure of one's conditions to significant others did providers and patients have similar expectations of stigma; these items also had higher levels of anticipated stigma compared with other dimensions. Health care providers were almost five times more likely to report the possibility of other types of psychosocial distress than were patients themselves. These included distress associated with social isolation within one's family, marital problems, and loss of income, suggesting that the disparity in anticipated consequences is broadly based and extends beyond social stigma. Because patients were newly diagnosed, it is unlikely that the explanation for their lower stigma scores was that they had become reconciled to their condition.[20] General understanding of latent TB is poor in the local community[25,28] and within the patient population studied;[29] thus, it is possible that the lower reported stigma and distress reflects lack of knowledge and experience with the condition. It is unclear whether the findings can be interpreted as minimization or denial of expected repercussions, as suggested in other studies of stigma.[22] The providers involved in TB services were presumably more knowledgeable than the patients about the condition and perhaps in a better position to assess the possibility of negative psychosocial consequences, and in addition they may have based their responses on personal experience dealing with active TB patients, who experience greater social isolation and stigma because of the transmissibility of the disease. Providers may draw upon experience with the psychosocial consequences of a contagious disease, and may perhaps overgeneralize their expectations for what is likely to occur for patients diagnosed with non-contagious latent TB.

The findings suggest that health care providers may overestimate the likelihood that patients diagnosed with LTBI will experience negative consequences, and this in turn may affect their interactions with patients. Concern about the negative repercussions for patients may lead to reluctance on the part of providers to advise or offer their patients to be tested for latent TB. This concern is documented in the TB literature[37–38] and was raised during in-depth interviews with several providers. Thus, from a public health perspective, the belief that patients diagnosed with a stigmatized condition will experience negative consequences may negatively affect adherence to TB testing guidelines.

The identification of disclosure concerns as the most important part of anticipated stigma points to the need for careful attention to the organization of TB testing and treatment services. In Florida, testing and treatment for tuberculosis, including both active and latent forms, are concentrated almost exclusively in the public sector, with most counties operating a separate TB clinic within the local health department. Segregated clinics inherently pose risks for disclosure of one's diagnosis because one's simple presence at the clinic may reveal the condition to others. In one of the counties of the study, TB services were housed in a separate building along with HIV and sexually transmitted diseases, conditions that are also stigmatized, so that merely entering the building ran the risk of someone experiencing “spoiled identity.”[39] In the other county, TB services were housed in a section of an older building with a “back door” entrance that allowed patients to avoid passing through the front lobby. In communities with heavy caseloads, such as those in Florida, segregated TB clinics are the most practical and cost-effective model of service delivery. However, care must be taken to minimize unnecessary exposure of patients to loss of confidentiality.

Ideally patients with stigmatized conditions such as LTBI, HIV and STDs should be treated within general clinics that provide a broad spectrum of adult health services so that care-seeking does not reveal one's diagnosis. However, over the past few decades county health departments have largely gotten out of the business of primary health care, so general clinics are rarely available for treating patients with these infections. Greater confidentiality can be ensured in the private sector, and LTBI patients in this study and in previous research with this population expressed a preference for obtaining care from private physicians for reasons of privacy.[25] However, physicians in private practice are reluctant to treat TB patients, including LTBI patients, because of the specialized and variable protocols involved, so they refer TB-related cases to the health department (which also provides medications and care at either reduced fees or free of charge). In the case of LTBI, however, for which treatment is voluntary, concerns about stigma on the part of providers may inhibit referral of patients for LTBI testing and treatment at health department clinics because of confidentiality risks.

Research on stigma perception among health care providers is sparse in general and virtually non-existent for tuberculosis. The finding that providers have a higher degree of perceived stigma associated with latent TB than patients themselves points to a possible deficiency in health education and public health practice.[6,8,40] Ensuring that health care providers serving patients at higher risk for TB are trained appropriately is an important step to ensure optimal care and adherence to appropriate TB screening guidelines. Furthermore, health departments alone cannot tackle the problem of LTBI among at-risk populations. An informed and capable private sector serving high-risk populations will be a critical part of eliminating TB as a public health problem in the United States.[41] A focus group needs assessment of private sector Haitian physicians in the study community conducted in 2001 reported that local providers embrace the idea of becoming more involved in TB case management, but they pointed to the need for further training in this area, along with greater coordination with and support from the public sector in order to do so effectively.* Public-private partnerships for TB control in the U.S. have received increasing attention and offer an important component for achieving national TB elimination priorities.[42] The research presented in the current study indicates that provider training in TB-related stigma processes may positively influence the development of these connections and skills and help promote national TB goals.

---

[*] Heurtelou, M. Haitian cultural study phase II. Unpublished report, ND.

## Acknowledgments

Support for the study was provided through grant no. 1-R01-TW06320 from the NIH Fogarty International Center (2003–08). The authors appreciate the assistance of tuberculosis program staff in the two county health departments participating in the study.

## References

1. Heijnders M, Van der Meij S. The fight against stigma: an overview of stigma-reduction strategies and interventions. Psychol Health Med. Aug; 2006 11(3):353–63. [PubMed: 17130071]
2. Van Brakel WH. Measuring health-related stigma—a literature review. Psychol Health Med. Aug; 2006 11(3):307–34. [PubMed: 17130068]
3. Chowdhury AN, Chakraborty AK, Weiss MG. Community mental health and concepts of mental illness in the Sundarban Delta of West Bengal, India. Anthropol Med. 2001; 8(1):109–29.
4. Link BG, Yang LH, Phelan JC, et al. Measuring mental illness stigma. Schizophr Bull. 2004; 30:511–41. [PubMed: 15631243]
5. Cross H. Interventions to address the stigma associated with leprosy: a perspective on the issues. Psychol Health Med. Aug; 2006 11(3):367–73. [PubMed: 17130073]
6. Deacon H, Boulle A. Commentary: factors affecting HIV/AIDS-related stigma and discrimination by medical professionals. Int J Epidemiol. Feb; 2007 36(1):185–6. Epub 2006 Dec 14. [PubMed: 17169944]
7. Sriram TG, Jabbarpour YM. Are mental health professionals immune to stigmatizing beliefs? Psychiatr Serv. May.2005 56(5):610. [PubMed: 15872176]
8. Ruiz-Torres, Y. Does training make a difference? AIDS stigma among health professionals from the social and medical sciences.. Poster Exhibition: The XV International AIDS Conferences. Abstract no. MoPeD3830
9. Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. Psychol Health Med. Aug; 2006 11(3):277–87. [PubMed: 17130065]
10. Link BG, Phelan JC. Conceptualizing stigma. Annu Rev Sociol. 2001; 27:363–85.
11. Stuber J, Meyer I, Link B. Stigma, prejudice, discrimination and health. Soc Sci Med. Aug; 2008 67(3):351–7. Epub 2008 Apr 25. [PubMed: 18440687]
12. Scambler G, Heijnders M, van Brakel WH. Understanding and tackling health-related stigma. Psychol Health Med. Aug; 2006 11(3):269–70. [PubMed: 17130063]
13. Nyblade LC. Measuring HIV stigma: existing knowledge and gaps. Psychol Health Med. Aug; 2006 11(3):335–45. [PubMed: 17130069]
14. Pescosolido BA, Martin JK, Lang A, et al. Rethinking theoretical approaches to stigma: a Framework Integrating Normative Influences on Stigma (FINIS). Soc Sci Med. Aug; 2008 67(3): 431–40. Epub 2008 Apr 22. [PubMed: 18436358]
15. Stuber J, Galea S, Link BG. Smoking and the emergence of a stigmatized social status. Soc Sci Med. Aug; 2008 67(3):420–30. Epub 2008 May 16. [PubMed: 18486291]
16. Somma D, Bond V. Special issue: perspectives on health-related stigma. Psychol Health Med. 2006; 11(3)
17. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Soc Sci Med. Jul; 2003 57(1):13–24. [PubMed: 12753813]
18. Scambler G. Sociology, social structure and health-related stigma. Psychol Health Med. Aug; 2006 11(3):288–95. [PubMed: 17130066]
19. Weiss MG. Stigma and the social burden of neglected tropical diseases. PLoS Negl Trop Dis. May 14.2008 2(5):e237. [PubMed: 18478049]
20. Brieger WR, Oshiname FO, Ososanya OO. Stigma associated with onchocercal skin disease among those affected near the Ofiki and Oyan Rivers in western Nigeria. Soc Sci Med. Oct; 1998 47(7):841–52. [PubMed: 9722105]
21. Pan-African Study Group on Onchocercal Skin Disease. The importance of onchocercal skin disease. World Health Organization; Geneva, Switzerland: 1995.

22. Vlassoff C, Weiss M, Ovugta EBL, et al. Gender and the stigma of onchocercal skin disease in Africa. Soc Sci Med. May; 2000 50(10):1351–68.
23. Farmer, P. Infections and inequalities: the modern plagues. University of California Press; Berkeley, CA: 2001.
24. Cain KP, Benoit SR, Winston CA, et al. Tuberculosis among foreign-born persons in the United States. JAMA. Jul 23; 2008 300(4):405–12. [PubMed: 18647983]
25. Coreil J, Lauzardo M, Heurtelou M. Cultural feasibility assessment of tuberculosis control among people of Haitian origin in South Florida. J Immigr Health. Apr; 2004 6(2):63–9. [PubMed: 15014223]
26. Granich RM, Zuber PL, McMillan M, et al. Tuberculosis among foreign-born residents of southern Florida, 1995. Public Health Rep. 1998; 113(6):552–6. Nov–Dec. [PubMed: 9847928]
27. Nachman SR. Wasted lives: tuberculosis and other health risks of being Haitian in a U.S. detention camp. Med Anthropol Q. 1993; 7(3):227–59.
28. Coreil J, Mayard G, Simpson K, et al. Structural forces and the production of tuberculosis-related stigma among Haitians in two contexts. Soc Sci Med. Oct; 2010 71(8):1409–17. Epub 2010 Aug 5. [PubMed: 20724052]
29. Coreil J, Lauzardo M, Clayton H. Stigma and therapy completion for latent tuberculosis among Haitian-origin patients. Fla Public Health Rev. 2010; 7:32–8.
30. Weiss MG. Cultural epidemiology: an introduction and overview. Anthropol Med. 2001; 8(1):5–29.
31. Weiss MG, Doongaji DR, Siddhartha S, et al. The Explanatory Model Interview Catalogue (EMIC): contribution to cross-cultural research methods from a study of leprosy and mental health. Br J Psychiatry. Jun.1992 160:819–30. [PubMed: 1617366]
32. Weiss MG, Somma D, Karim F, et al. Cultural epidemiology of TB with reference to gender in Bangladesh, India and Malawi. Int J Tuberc Lung Dis. Jul; 2008 12(7):837–47. [PubMed: 18544214]
33. Lauzardo M, Duncan H, Szwed T, et al. Tuberculosis among individuals of Haitian origin in Florida: opportunities for intervention. Am J Respir Crit Care Med. 2001; 163(5) Part 2, A-100.
34. Farmer, P. AIDS and accusation: Haiti and the geography of blame. University of California Press; Berkeley, CA: 1992.
35. Stepick, A. Pride against prejudice: Haitians in the United States. Allyn & Bacon; Boston, MA: 1998.
36. Faugier J, Sargeant M. Stigma: its impact on professional responses to the needs of marginalised groups. Journal of Research in Nursing. May; 1997 2(3):220–9.
37. Joseph HA, Shrestha-Kuwahara R, Lowry D, et al. Factors influencing health care workers' adherence to work site tuberculosis screening and treatment policies. Am J Infect Control. Dec; 2004 32(8):456–61. [PubMed: 15573052]
38. Lazar CM, Sosa L, Lobato MN. Practices and policies of providers testing school-aged children for tuberculosis, Connecticut, 2008. J Community Health. Oct; 2010 35(5):495–9. [PubMed: 20087634]
39. Goffman, E. Stigma: notes on the management of spoiled identity. Simon and Schuster; New York, NY: 1963.
40. Sadow D, Ryder M, Webster D. Is education of health professionals encouraging stigma towards the mentally ill? J Ment Health. 2002; 11(6):657–65.
41. Geiter, L., editor. Ending neglect: the elimination of tuberculosis in the United States. National Academy Press; Washington, DC: 2000. The Ad Hoc Committee on Tuberculosis. Mobilizing for elimination..
42. Bagchi, CP.; Miodovsdi, R. Centers for Disease Control and Prevention; Atlanta, GA: 2010. Los Angeles County collaborates with private medical community on symposium on public-private partnerships to control TB.. Available at: http://www.cdc.gov/tb/publications/newsletters/notes/TBN_2_10/highlights.htm

## Box 1. ITEMS IN STIGMA INDEX

Internal Perceptions and Emotions

Think less of self

Patient: Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?

Provider: Would Marie Rose think less of herself because she has this condition? Might she have less pride or self-respect?

Feel ashamed

Patient: Have you ever been made to feel shamed or embarrassed because of this problem, or are you concerned that this might happen?

Provider: Do you think Marie Rose might feel ashamed or embarrassed because of this problem?

External Perceptions

Others less respect

Patient: 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?

Provider: If others in the community came to know about it, would they have less respect for Marie Rose?

Think less of family

Patient: If they knew about it, would your neighbors, colleagues or others in your community think less of your family because of this problem?

Provider: If others in the community came to know about it, would they have less respect for Marie Rose's family?

Assume other health problems

Patients: 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?

Provider: Even if Marie Rose didn't have any other health problems, are people likely to think she does because she has the TB germ?

Assume have TB disease

Patients: Are you concerned that others will assume that you have the real TB disease?

Providers: Might people assume she has the real TB disease?

Assume have HIV

Patients: Are you worried that people will assume you have HIV?

Providers: Would people assume she has HIV?

External Actions

Problems for children

Patient: (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?

Provider: Do you think the problem might cause social problems for Marie Rose's children in the community?

Problems at work

Patient: 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?

Provider: Would this condition cause problems for Marie Rose at work if people knew about it?

Difficult to marry

Patient: (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?

Provider: If she were unmarried, do you feel that even after having received treatment and having been cured, Marie Rose would have difficulty to get married, as a result of this illness?

Others avoid

Patient: Do you feel others have avoided or might avoid you because of this problem?

Provider: Do you think others might avoid Marie Rose because of this problem?

People refuse to visit

Patient: Would some people refuse to visit your home because of this condition even after you have been treated?

Provider: Would other people refuse to visit Marie Rose's home because of this condition even after treatment?

Disclosure

Hide problem from others

Patient: If possible, would you prefer to keep people from knowing about this problem?

Provider: Do you think Marie Rose would prefer to keep others from knowing about this problem?

Disclose to family

Patient: Have you discussed or do you plan to discuss this with family members?

Provider: Do you think that Marie Rose would discuss this with family members?

Disclose to friend

Patient: Have you discussed or do you plan to discuss this with close friends?

Provider: Do you think that Marie Rose would discuss this with close friends?

Disclose to neighbors

Patient: Have you discussed or do you plan to discuss this with neighbors?

Provider: Do you think that Marie Rose would discuss this with neighbors?

Disclose to church members

Patient: Have you discussed or do you plan to discuss this with church members?

Provider: Do you think that Marie Rose would discuss this with church members?

Disclose to co-workers

Patient: Have you discussed or do you plan to discuss this with co-workers

Provider: Do you think that Marie Rose would discuss this with co-workers?

Haitian Identity

More embarrassing because Haitian

Patient: Is it more embarrassing for you to have a TB-related condition because you are Haitian than it would be for other people in Florida?

Provider: Is it more embarrassing for Marie Rose to have the TB germ because she is Haitian than it would be for other people in Florida?

Others think worse because Haitian

Patient: Because you are Haitian will people think worse of you than others with the same TB condition?

Provider: Because Marie Rose is Haitian will people think worse of her than others with the TB germ?

## Table 1

DEMOGRAPHIC CHARACTERISTICS OF SURVEY SAMPLE

| | Health Care Providers | Patients |
|---|---|---|
| Age (mean years) | 46.5 | 38.1 |
| Gender (% female) | 70.8 | 60.0 |
| Education (mean years) | 15.5 | 11.6 |
| Income (mean annual) | $40,408 | $12,793 |
| Years living in U.S. (mean) | 22.2 | 6.1 |
| Religion (%) | | |
| Protestant | 31.0 | 54.6 |
| Catholic | 47.6 | 30.0 |
| None/other | 21.4 | 15.5 |
| Marital status (%) | | |
| Single | 14.6 | 34.4 |
| Married/Partnered | 64.6 | 58.9 |
| Divorced | 16.7 | 3.3 |
| Widowed | 4.2 | 3.3 |

## Table 2

MEAN SCORES FOR STIGMA ITEMS AND COMPOSITE SCORE BY GROUP

| Item[a] | Health Care Providers (N=43) Mean (SD) | Patients (N=90) Mean (SD) |
|---|---|---|
| Think less of self* | 0.79 (1.1) | 0.33 (0.95) |
| Feel ashamed*** | 1.19 (1.2) | 0.36 (0.93) |
| Others less respect* | 0.81 (1.12) | 0.43 (0.98) |
| Less respect for family | 0.84 (1.13) | 0.66 (1.09) |
| Assume other health problems* | 1.30 (1.35) | 0.67 (1.09) |
| Assume have TB disease*** | 1.63 (1.29) | 0.51 (1.09) |
| Assume have HIV** | 0.95 (1.17) | 0.37 (0.96) |
| Problems for children | 0.84 (1.13) | 0.64 (1.11) |
| Problems at work*** | 1.09 (1.15) | 0.11 (0.54) |
| Difficult to marry | 0.40 (0.88) | 0.42 (0.93) |
| Others avoid** | 0.98 (1.13) | 0.40 (1.00) |
| People refuse to visit | 0.74 (1.03) | 0.44 (0.96) |
| Hide problem from others*** | 2.49 (0.80) | 1.18 (1.37) |
| Disclose to family | 0.93 (1.16) | 0.81 (1.11) |
| Disclose to friends | 1.73 (1.05) | 1.69 (1.16) |
| Disclose to neighbors | 2.66 (0.76) | 2.47 (0.84) |
| Disclose to church members | 2.39 (0.83) | 2.16 (1.00) |
| Disclose to co-workers | 2.63 (0.77) | 2.31 (0.95) |
| More embarrassing because Haitian*** | 1.39 (1.33) | 0.60 (1.09) |
| Others think worse because Haitian*** | 1.44 (1.33) | 0.57 (0.99) |
| Composite score*** | 26.6 (14.7) | 17.1 (9.8) |

[a] Mean scores per item were the average score on a Likert scale of 0-3, with three representing the highest level of stigma.

* p<.05

** p<.01

*** p<.001

## Table 3

ANTICIPATED PSYCHOSOCIAL DISTRESS BY GROUP

| Type of Distress | Health Care Providers (N=43) Frequency reported yes (%) | Patients (N=90) Frequency reported yes (%) |
|---|---|---|
| Isolation within family | 3 (7.0) | 2 (2.2) |
| Problems within family | 3 (7.0) | 0 (0.0) |
| Social isolation | 4 (9.3) | 3 (3.3) |
| Social stigma | 10 (23.3) | 3 (3.3) |
| Marital problems | 4 (9.3) | 1 (1.1) |
| Loss of job | 5 (11.6) | 3 (3.3) |
| Reduced income | 5 (11.6) | 2 (2.2) |
| Sadness, worry or stress | 21 (48.8) | 15 (16.7) |
| Anxiety regarding job | 5 (11.6) | 2 (2.2) |
| Anxiety regarding finances | 5 (11.6) | 3 (3.3) |
| Anxiety regarding family | 6 (14.0) | 2 (2.2) |