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Structural forces and the production of TB-related stigma among Haitians in two contexts

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ABSTRACT

In recent years renewed interest in health-related stigma has underscored the importance of better understanding the structural underpinnings of stigma processes. This study investigated the influence of sociocultural context on perceived components of tuberculosis-related stigma in non-affected persons by comparing Haitians living in South Florida, USA, with Haitians residing in Léogane Commune, Haiti. Using the methods of cultural epidemiology, a two-phase study based on fieldwork between 2004 and 2007 collected ethnographic data on the cultural context and components of tuberculosis (TB) stigma, and administered a stigma scale developed specifically for these populations. Thematic analysis of stigma components expressed in interviews, focus groups and observation revealed commonalities as well as distinctive emphases of TB stigma in the two comparison groups. Factor analyses of stigma scale scores confirmed the thematic differences revealed in ethnographic findings and highlight the influence of political and economic factors in shaping the meaning and experience of illness. Perceived components of TB stigma among Haitians in South Florida incorporated aspects of Haitian identity as a negatively stereotyped minority community within the larger society, while in Haiti, stigma was associated primarily with poverty, malnutrition, and HIV co-infection. Discussion of findings focuses on the social production of perceived and anticipated stigma as it is influenced by structural forces including the influences of politics, economics, institutional policies, and health service delivery structures. The findings also demonstrate the value of a transnational framework encompassing both sending and receiving countries for understanding TB-related stigma in immigrant communities.

Introduction

Greater attention in recent years to health-related stigma has highlighted the need for better understanding of the structural influences on stigma processes (Pescosolido, Martin, Lang, & Olafsdottir, 2008; Phelan, Link, & Dovidio, 2008; Scambler, 2006; Somma & Bond, 2006). Social relations of power, prejudice, discrimination and other structural dynamics in the production of stigma have gained currency in scholarly discourse (Link, Castille, & Stuber, 2008; Link & Phelan, 2001; Weiss, 2008). However, few empirical studies have been conducted on the influence of social structure on health-related stigma.

We investigated the influence of structural forces in the production of TB-related stigma among Haitians living in two very different sociopolitical contexts, the United States and Haiti. These contexts include political and economic forces that shape the meaning of illness experience, as well as institutional policies and practices that reinforce negative stereotypes or lead to discrimination (Corrigan, Markowitz, & Watson, 2004; Link & Phelan, 2001). Social context also affects cognitive components or attributions of meaning about stigma, including "anticipated stigma" (Weiss, 2008), based on the intersection of social structure and the social identity of stigma targets. Expectations and experience of stigma in one domain, such as illness, may be closely associated with other stigmatized identities and statuses (Stuber, Meyer, & Link, 2008). For example, health-related stigma may intersect with gender, ethnicity, social class and sexuality (Allotey & Gyapong, 2008; Collins, von Unger, & Armbgrister, 2008). In the case of Haitians,

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whose national identity itself has been the focus of prejudice and negative stereotypes in the global media, and particularly within American society (Farmer, 1992; Granich et al., 1998; Nachman, 1993), the potential for TB-related stigma to reflect larger social forces is noteworthy.

This report analyzes findings from a cross-national study that investigated the influence of sociocultural context on tuberculosis-related stigma by comparing the components of perceived and anticipated stigma in an immigrant population with those found in the country of origin. The comparison groups were Haitians residing in South Florida and Haitians living in Haiti. The sociocultural context in this study is comprised of both the larger society and the local communities in which people live. In the U.S. it includes national and local media stories and images of immigrant groups, as well as government, health, education, and religious institutions, among many others, that interact with and shape public perceptions of ethnic minority populations. In Haiti, the sociocultural context differs dramatically from that of the U.S. There, the concepts of immigrant or ethnic minority status have little meaning, and the context is profoundly shaped by extreme economic, environmental and political conditions.

The social history of tuberculosis also differs considerably in the two settings. In Haiti tuberculosis has remained a leading cause of death since colonial times, and is associated with poverty, misery and HIV infection. In the U.S., tuberculosis declined markedly in the 20th century, then experienced a resurgence with the AIDS epidemic. In recent years TB became associated with immigration from endemic countries such as Haiti, and thus is viewed as a problem of "foreign-born" populations (Cain, Benoit, Winston, & MacKenzie, 2008), and the condition tends to be "blamed" on the immigrant groups themselves. Additionally, as Haitian Americans are an ethnic minority within a larger industrialized society, the pressure to assimilate to the host culture impacts both identity and social interactions in a way not found in home country settings. These circumstances allow us to investigate the influence of structural factors on perceived stigma.

The transnational framework of the study is significant not only for understanding social determinants of stigma, but also from the standpoint of current perspectives on immigration experience, ethnic minority identity, and the epidemiology of tuberculosis in the United States. The image of Haiti and its people in the American imagination, shaped by enduring stereotypes, selective media coverage, discriminatory U.S. immigration policies and global disease history, profoundly influences the situation of Haitians living in the United States (Farmer, 1992; Stepick, 1998). Furthermore, in areas such as South Florida, where Haitians number significantly within immigrant groups, public concern about tuberculosis has been disproportionately associated with Haitian immigration (Coreil, Lauzardo, & Heurtelou, 2004; Granich et al., 1998; Nachman, 1993; Stepick, 1992).

The organization of TB services itself reflects the convergence of disease concerns and immigration. In Florida, public health programs related to tuberculosis and immigrant groups are jointly served by the Bureau of Tuberculosis and Immigrant Health. On World TB Day 2004 (March 24), the Bureau sent out a press release announcing the increase in TB cases state-wide from the previous year. The statement noted that a large number of the new cases were diagnosed among "foreign-born" persons. A follow-up interview by a media source revealed that Haitians made up more than half of the TB cases in the foreign-born group. The following day, a National Public Radio broadcast reported that tuberculosis rates were on the rise in Florida because of Haitian immigration to the state. The media have been an important force in perpetuating negative stereotypes of Haitians in the United States.

Stigma and tuberculosis

The study of tuberculosis provides a powerful lens through which to view the impact of structural forces on the production of stigma (Farmer, 1999; Macq, Solis, & Martinez, 2006), including perceived stigma. Throughout the ages, societal attitudes and behavior toward this disease have been infused with shame, rejection, discrimination and neglect. In the 20th century, improved living conditions in urban areas and the availability of antibiotic drugs dramatically reduced TB prevalence as well as the social stigma associated with it. However, as the 20th century came to a close, erosion of public health funding and infrastructure worldwide, along with the reemergence of TB as a co-infection with HIV/AIDS, led to restigmatization of TB (Coreil, 2010).

In developing countries, where tuberculosis has remained a leading cause of mortality for centuries, the disease continues to be stigmatized because of its association with poverty, discrimination and contagion. Although the availability of effective antibiotic therapy undoubtedly lowered the degree of TB stigma associated with disease communicability, exaggerated notions of transmissibility and fear of the disease continue to produce stigmatizing effects (Long, Johansson, Diwan, & Winkvist, 2001; Weiss, Auer, et al., 2006).

The situation has improved somewhat today, yet the disease continues to be stigmatized because of its enduring association with marginalized and disenfranchised groups, and particularly with HIV co-infection. Research conducted in HIV/AIDS endemic areas has shown that even HIV-negative TB patients are suspected of having AIDS, and this may cause delays in seeking TB care and treatment non-adherence (Møller & Erstad, 2007; Ngamvithayapong, Winkvist, & Diwan, 2000).

Farmer (1997, 1999) has criticized both biomedical and social science research for overemphasizing the influence of cultural beliefs and social stigma on treatment outcomes such as patient compliance, calling for greater attention to structural barriers to health care. Similarly, Das (2001) documents how state institutions in India obstruct the reintegration of TB patients with society even after their disease has been cured. Furthermore, the role of racism in the production of disease-related stigma must be taken into account. The early unfounded labeling of Haitians as a "risk group" for AIDS in the United States reflected both racial bias and the tendency to attribute blame for contagion to foreign immigrants (Farmer, 1992). Moreover, tuberculosis has long been linked with people of African origin in the United States (Wailoo, 2001). Our study design allowed us to expose dimensions of stigma that might be influenced by racial prejudice.

Study aims and oversight

The aims of the study were twofold: first, to identify the components of stigma perceived as important within non-affected community samples in the two study populations; and second, to understand the contextual influences on these stigma components across sites. Ethical oversight of the study was provided by Institutional Review Boards of the University of South Florida, the Florida Department of Health and Hôpital Ste. Croix in Haiti.

Methods

Our study used a mixed method approach that combined qualitative and quantitative techniques. Fieldwork was conducted between 2004 and 2007. The study design is based on the methodology of cultural epidemiology which integrates multi-phased data collection with interactive quantitative-qualitative survey instruments (Weiss, 2001). The basic instrument in cultural epidemiology is the Explanatory Model Interview Catalog (EMIC), which is developed

for specific health conditions and cultural settings based on ethnographic research to construct items related to perceived causes, patterns of distress and help-seeking. The methodology has been tested and refined across a broad range of geographic settings and illness problems, including tuberculosis (Chowdhury, Chakraborty, & Weiss, 2001; Vlassoff et al., 2000; Weiss, Auer, et al., 2006; Weiss, Ramakrishna, et al., 2006). The design combines traditional epidemiologic methods with anthropological techniques to produce culturally valid measures of illness representations and their distributions in local populations. Cultural validity refers to the meaningfulness of the elements of a cultural domain for the population being studied. The particular set of topics investigated varies depending on the illness condition, cultural context, and population targeted. General categories of inquiry include types of illness-related distress (including stigma), perceived causes, and help-seeking patterns. These topics guide the development of questions to be addressed in the ethnographic components of the study. It involves two phases: Phase I collects ethnographic data to identify important cultural components of the condition in order to contextualize the problem and to inform development of a semi-structured instrument (the EMIC); and Phase II administers the instrument in defined subpopulations for subsequent comparisons across groups.

Phase I

In Phase I of our study, qualitative data collection techniques included participant observation at 6 clinics (20 h each) and 3 health fairs, in-depth interviews ($N = 182$), focus group discussions ($N = 12$), and media monitoring (local radio, television, newspapers). Two research teams collected data in Broward and Palm Beach counties in South Florida and Léogane Commune, Haiti. The 2000 Census estimated 618,976 Haitian origin persons living in the United States, including 10.6% in Broward County and 6.1% in Palm Beach County. Interview guides included questions related to how Haitians are viewed in South Florida, health problems in the Haitian community, individual and collective behavior related to stigmatized illnesses, explanatory models of tuberculosis, and the impact of tuberculosis on affected individuals.

Three subpopulations comprised our sample in each country site: community residents, TB patients, and health care providers. Ethnographic data from all three groups were used to better understand context and to develop the survey instruments used in Haiti and South Florida. Community residents were recruited using organization-based quota sampling (Bernard, 2006), a technique that involves recruitment of research participants from local organizations that are closely affiliated with the study population. Five types of organizations serving Haitian communities in the U.S. and Haiti were targeted, churches, schools, businesses, civic/cultural organizations and social service agencies. Between 3 and 5 different organizations were contacted from each of the 5 categories in each setting. Churches were the place of recruitment for 19% of interviewees, schools for 18%, businesses for 23%, civic/cultural organizations for 18%, and social service agencies for 22%. An initial contact in each organization assisted us in identifying other potential interviewees. Health care providers and TB patients were recruited from tuberculosis clinics (health department, refugee and private clinics in Florida, and a public hospital outpatient clinic in Haiti). In addition to the interview topics noted above, health care providers were asked about their experience caring for tuberculosis patients, challenges of providing care to culturally diverse populations, and the difficulties faced by TB patients. All interview guides were pretested with 2 participants from each sub-group.

Once in-depth interviews, participant observation and media monitoring were completed and analyzed, draft EMIC instruments were developed for use in the Phase II cultural epidemiologic study. We next conducted focus groups to validate the accuracy and completeness of the draft instrument. A total of 12 focus group discussions were conducted, 2 with each subsample of community residents, providers and patients in each site.

The sample breakdown for individuals who participated in interviews and focus groups is summarized in Table 1. A total of 182 in-depth interviews were conducted during the ethnographic phase, including 81 in Florida and 101 in Haiti. In addition, 111 men and women participated in focus group discussions, for a total of 293 research participants in the ethnographic phase.

Data from the Ethnographic Study were managed through the qualitative analysis software program MAXQDA® (VERBI Software. Berlin-Marburg-Amöneburg, Germany 2007). Field notes from participant observation, transcripts of interviews and focus group discussions, and demographic data were entered into the data base. Finally, documents collected through field research and media monitoring were indexed and catalogued. In-depth content analysis of ethnographic data was undertaken to identify thematic priorities of importance for the study populations. These identified priorities in local explanatory models of tuberculosis helped us to adapt an existing EMIC instrument in ways to enhance the local validity of its content for two very different sociocultural contexts.

Phase II

In Phase II of the study we developed a semi-structured instrument, the EMIC for Tuberculosis in Haitian Populations, which was adapted from a similar instrument developed for a multi-country study of tuberculosis and gender (Somma et al., 2008; Weiss, 2008). That instrument is organized into 4 sections that address a person's understanding of the condition (naming and framing), perceived causes, experienced or anticipated types of distress (including stigma), and patterns of help-seeking. Based on our ethnographic findings, we modified the original EMIC instrument to include locally valid content and language, including a set of items designed to measure tuberculosis-related stigma, which we refer to as the Stigma Scale. Separate versions of the scale were developed for the two comparison sites in our study based on themes that emerged in the ethnographic findings. For example, because of the impact that

Table 1
Sample matrix for interviews and focus groups by site and sub-groups.

	Community	Providers	Patients	Total
Interviews				
Florida	24	24	33	81
Haiti	32	17	52	101
Total	56	41	85	182
Focus groups	No. of groups (# participants)	No. of groups (# participants)	No. of groups (# participants)	No. of groups (# participants)
Florida	2 (19)	2 (12)	2 (16)	6 (47)
Haiti	2 (20)	2 (19)	2 (25)	6 (64)
Total	4 (39)	4 (31)	4 (41)	12 (111)
Total (individuals)	95	72	126	293

co-infection with HIV has on stigma related to TB in this population, we included an item that addresses this issue ("Even if Jean didn't have any other health problems, are people likely to think he does because he has TB?" and "Would people assume he has HIV?"). A distinctive feature of our EMIC instrument was the inclusion of items related to perceived stigma and discrimination related to Haitian identity in the U.S., as discussed further in the next section ("Is it more embarrassing for Jean to have TB because he is Haitian than it would be for other people in Florida?" and "Because Jean is Haitian, will people think worse of him than others with TB?"). The final instruments included 22 items (Haiti) and 24 items (Florida) respectively, addressing issues related to internal perceptions and emotions, disclosure, external perceptions, external actions, courtesy stigma (effects on significant others), and Haitian identity (Florida only).

The items included in the Stigma Scale, along with their mean scores by site, are presented in Table 2. These items were selected in part on the basis of extensive exploratory factor analysis for each site separately, and were subsequently used to derive composite stigma scales. Though the scales differed to some degree in item number and content, the two scales shared 22 core items (91.6%). Internal consistency of the scales was good, with Chronbach alpha scores greater than .80. Although traditional cross-cultural comparisons often rely on standardized instruments containing identical items, the EMIC approach is designed to compare findings with reference to a locally valid theoretical maximum, rather than an absolute measure of stigma. Insofar as such an assessment is conducted with reference to a local baseline, assessments and comparisons across groups are meaningful.

Because illness labels and meanings vary by local context, to standardize the content in both settings we presented a case vignette of someone with symptoms of active tuberculosis in order to have respondents focus on a comparable condition. The following case vignette was used:

> Jean is 35 years old. He and his wife have been married for seven years, and they have 2 children. He has been suffering from cough and a fever for two months. He keeps bringing up phlegm while coughing. He does not have any appetite and has lost a lot of weight. He feels so weak that he is unable to go to work every day.

Phase II data collection consisted of administering the EMIC instrument to comparison groups of community residents, patients and providers in both sites. This paper reports survey findings from

Table 2
Stigma scale items, abbreviated labels, and mean scores* by site.

Factor Label and Scale Items	Item abbreviation	Mean scores Haiti	Mean scores Florida
Internal perceptions and emotions.			
Would Jean think less of himself because he has TB? Might he have less pride or self-respect?	Think less of self	2.36	2.06
Do you think Jean might feel ashamed or embarrassed because of this problem?	Feel ashamed	2.57	2.34
Would Jean be worried that he might have to spend time in a TB hospital/sanatorium?	Worry about sanatorium	1.15	2.35
Disclosure			
Do you think Jean would prefer to keep others from knowing about this problem?	Hide from others	1.70	2.64
Do you think that Jean would discuss this problem with family members?	Disclose to family	1.00	.59
Do you think that Jean would discuss this problem with close friends?	Disclose to friends	1.48	1.49
Do you think that Jean would discuss this problem with neighbors?	Disclose to neighbors	2.16	2.03
Do you think that Jean would discuss this problem with church members?	Disclose to church members	1.56	1.82
Do you think that Jean would discuss this problem with co-workers?	Disclose to co-workers	1.77	2.27
External perceptions			
If others in the community came to know about it, would they have less respect for Jean?	Loss of respect	1.99	1.49
Would others believe that Jean is dangerous because of this condition?	Think dangerous	2.23	2.39
Even if Jean didn't have any other health problems, are people likely to think he does because he has TB?	Assume has other conditions	2.61	2.31
Would people assume he has HIV?	Assume has HIV	2.72	2.31
External actions			
Do you think people might say or do anything to hurt Jean because of his illness?	Others hurtful	2.38	1.14
Do you think others might avoid Jean because of this problem?	Others avoid	2.38	2.46
Would other people refuse to visit Jean's home because of this condition even after treatment?	Others refuse to visit	1.01	1.95
Would this condition cause problems for Jean at work if people knew about it?	Problems at work	2.21	2.33
Do you think that Jean's wife will remain with him and be supportive over the entire course of the treatment?	Wife supportive	.64	.18
If Jean were unmarried, do you feel that even after having received treatment and having been cured, Jean might still have difficulty getting married, as a result of his illness?	Difficulty marrying	1.02	.91
Courtesy stigma			
If others in the community came to know about it, would *they* have less respect for Jean's family?	Less respect for family	1.99	1.49
If he had children, do you think the problem might cause social problems for Jean's children in the community?	Problems for children	1.09	1.46
Would contact with Jean have bad effects on others around him even after he is treated?	Effects on others	1.10	.60
Haitian identity			
Is it more embarrassing for Jean to have TB because he is Haitian than it would be for other people in Florida?	Embarrassing because Haitian	NA	1.76
Because Jean is Haitian, will people think worse of him than others with TB?	Think worse because Haitian	NA	1.91

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

the community samples only in Haiti ($N = 100$) and Florida ($N = 98$). This allowed us to focus on active TB in both settings, because latent TB is not well understood among Haitian lay persons, and only active TB patients are treated routinely in that setting. Comparison of patients and providers is more complicated because our sample involved latent TB patients and services in Florida, which are not comparable with Haiti, and thus have been excluded in this analysis. Participants were selected using organization-based quota sampling as described for Phase I. Descriptive, bivariate and multivariate statistical analyses were conducted using SAS Software Version 9.1® (SAS 2005). Demographic characteristics of the two samples are presented in Table 3. Comparisons were made across groups to test for mean differences in composite stigma scale scores.

Coding of responses for each item in the Stigma Scale ranges from 0 to 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, and dividing by the total possible scale score, resulting in a percent value. Thus the reported composite scores range from 0 to 100, indicating that the assessment of stigma was made with reference to a theoretical maximum and based on locally validated indicators. The determination of items to include in the composite score was based on exploratory factor analysis (EFA) as described below.

Exploratory factor analyses were conducted to identify which items on the stigma scale grouped together to measure underlying constructs of stigma in each population. The sample sizes were in the conventional neighborhood of roughly 4–5 times the items. Eigenvalue (>1.0), cumulative variance, and scree plot criteria were utilized to identify and select the number of possible stigma components. Under these criteria initial analysis identified 6 and 7 factors for Florida and Haiti, respectively. Additional factor analyses were conducted with fewer factors along the line of statistical model comparison for optimal item distribution among stigma components. Model comparison also incorporated conceptual interpretability of each factor. The final model was then determined using goodness of fit criteria such as chi-squared test, Bentler's comparative index, factor loadings, and residual diagnostics. The Haiti model of stigma comprised five factors and 20 items while the Florida sample resulted in a four-factor model with 21 items. EFA analyses excluded two items (wife remains supportive, bad effects on others) from the Haiti model and three items (others think Jean dangerous, wife remains supportive, bad effects on others) from the Florida model because of insignificant loadings that were also difficult to interpret.

Table 3
Demographic variables: Florida and Haiti.

Variable	Florida	Haiti
Mean Age (years)	40.7	35.0
Males (%)	46.9	51.0
Mean years of schooL	12.5	10.5
Marital status (%)		
single	38.0	25.0
Married/partnered	50.0	65.0
Divorced/widowed	12.0	10.0
Income (mean yearly in USD)	15,243	3596
Employment (%)		
Full-time	55.1	31.0
Part-time	24.5	18.4
Unemployed	17.3	49.4
Retired	3.1	1.2
Religion (%)		
Protestant	41.2	29.0
Catholic	50.5	61.0
Voudou	4.1	6.0
Other	4.2	4.0
Literacy (% yes)	92.7	80.2
Type of organization (recruitment)		
Business	28.1	19.0
Church	18.8	20.0
Civic	16.7	19.0
School	15.6	20.0
Social services	20.8	22.0
Language of interview		
Creole	46.9	100
English	53.1	0

Results

Narrative accounts of tuberculosis-related stigma

This section elaborates on the ethnographic findings which highlight the social contextual factors that influence the production of stigma and which informed the identification of items included in the Stigma Scale. Analysis of interviews, focus group discussions and participant observation revealed both similarities and differences in the components of stigma emphasized in the two sites. In both settings, themes of shame, social isolation, and discrimination were invoked when discussing the impact of a TB diagnosis. Study participants discussed consequences such as being avoided by others, taking efforts to conceal the condition, effects on family relationships, and repercussions experienced by others. In both settings a recurrent theme was the close association between HIV and TB, and the perception that many people assume that someone who has TB is also HIV-infected. Fear of attributions of having other health conditions, and in particular HIV, was expressed by patients and confirmed by community members and health care providers. Finally, transnational themes were expressed in narratives of help-seeking and concealment, including references to patients in both countries seeking care in the other setting to protect anonymity, seek traditional healing in Haiti, or obtain regular TB treatment in the U.S.,

> "Yes, there is a relationship with AIDS. There are people who will keep their distance with TB as a manifestation of AIDS." (Interview with community resident, Haiti)
> "I find that within the Haitian community… when someone has TB, you will find that it is because they have been diagnosed with HIV or AIDS, and therefore it is part of the whole process. I am finding most of the times that they are both related to each other." (Interview with community resident, Florida)

TB-related stigma was also associated with the threat of incarceration for persons who do not comply with treatment protocols. The threat of court-ordered institutionalization in South Florida's tuberculosis hospital (A.G. Holley in Lantana, Florida) figured significantly in respondent narratives. Institutionalization for 6–9 months isolates patients from their families and communities, and often means loss of employment. Respondents likened being sent to A.G. Holley to being put in jail for a crime. In Haiti, institutional treatment at a local tuberculosis/leprosy sanatorium is based primarily on economic and clinical factors. Patients who are too poor to maintain healthy diets during treatment are referred to Hôpital Cardinal Léger located about 15 km from Léogane, which provides free meals to inpatients. Patients who have resistant or complicated cases of TB are also referred there for specialized care. Some patients welcome referral to the sanatorium for the special care provided, but many families are nevertheless embarrassed to disclose that a member is in treatment there because of its association with malnutrition, poverty and HIV.

The risk of loss of confidentiality and privacy related to help-seeking for TB were voiced in interviews among all groups. In both Haiti and Florida, tuberculosis treatment is largely confined to

public sector care where the organization of services may expose patients to the risk of having their conditions revealed to others. In both countries, TB patients are treated in special clinics or rooms so that simply seeking care can identify someone as having the disease. In Haiti, it was observed that sometimes clinic staff announces in the general waiting room, "All TB patients, please come forward." Everyone knows that to go into the "green" consultation room means the person is being treated for TB. Likewise, in Broward and Palm Beach counties TB clinics are separate and located in the same building as HIV and sexually transmitted disease services, thus exposing patients to identification with other stigmatized diseases. Furthermore, being visited by outreach workers for Directly Observed Therapy (DOT) is viewed negatively because it reveals one's condition to neighbors.

However, interesting contrasts in the influence of structural issues on perceived stigma were revealing. In Haiti, perceived TB stigma was primarily related to *economic* issues, while in Florida it was related to both economic and *political* issues. Haitian community respondents talked about the shame of TB being associated with poverty and malnutrition, and the fact that having a family member diagnosed with TB reflects badly on the family's ability to provide for its members, including food and adequate living space. Not being able to feed one's loved ones properly is a source of great shame, and people are cognizant of the association between cramped living quarters, disease transmission, and stigma.

> "In Haiti, many people consider this illness to be one associated with poor people. They see that in developing countries one finds more cases of TB." (Interview with health care provider, Haiti)
> "The [degree of humiliation] depends on the family's economic level. If the person already has a separate room with all of his belongings he won't feel bad but if the person is living in a one-room house with a bunch of other people he will naturally react to being given a separate sleeping mat." (Interview with community resident, Haiti)

Interestingly, Haitian narratives also emphasized how much things have changed in Haiti and that the disease is much less stigmatized today than in earlier times. In the past persons diagnosed with TB were isolated in a small hut in the back yard to protect other family members from exposure. One of the folk names for the disease, *maladi ti kay* (little house illness) derives from this custom. However, with the advent of effective antibiotic treatment, sick persons are no longer housed apart and considerable destigmatization of the disease has occurred. Nevertheless, the disease continues to be a source of shame, as poignantly illustrated during our study by a Haitian teacher from Port-au-Prince who commuted monthly to the Palm Beach County Health Department to obtain medication for active TB so that her colleagues and associates in Haiti would not know about her condition.

> "Long ago they used to humiliate persons with TB. They used to put them in a little house all alone and this made them feel ashamed. This is no longer done and those affected don't feel it is such a problem, and family and friends still come to visit them." (Interview with community resident, Haiti)

In Florida, the meaning of TB-related stigma was also related to poverty, as in Haiti, but in addition, it had a distinct association with Haitians being a socially marginalized and disadvantaged minority group. Themes of discrimination, particularly in relation to immigration policy, surfaced in stigma narratives. In addition, negative media stories, cultural differences and racism against Haitians in the U.S. were invoked. The top media stories during our study, which took place during a tumultuous time of the ouster of President Aristide as well as hurricanes and flooding, had headlines such as: "Haitians Cry Out for Justice," "Haiti Grapples with Violence and Lawlessness," "Unrest in Homeland Distressing Local Haitians," "U.S Should Honor Rights of Haitian Refugees," Haiti Handover As Floods Devour," Aristide starts exile in South Africa," and "Haiti the Eroding Nation." The following excerpts from interviews illustrate the perceived social construction of Haitians in the U.S.

> "The media portray us as last class, bad people that we have nothing to offer, because this is all they can reflect to the community, which is false because they don't get to know us. The themes that are emphasized are that we carry all kinds of diseases and we come here to take away people's jobs…" (Interview with community resident, Florida)
> "When they say Haitian, they put everything on us. If you are Haitian you will feel that pressure. Everybody targets you – for no reason – Why? Health issues, immigration, everything, social background, everything because there were some things bad for Haitians." (Interview with Haitian social worker, Florida)
> "Haitians are victims of double prejudice; first they are black and then they are also Haitian so that has a double negative impact on them. " (Interview with TB patient, Florida)

The themes related to social attitudes toward Haitians as a minority group warrant further elaboration. These included stereotypes of Haitians having brought HIV to the U.S., being sources of contagion for TB and other infectious diseases, and being unfairly targeted for TB screening "just because we're Haitian." In accordance with current CDC policy, immigrants from high-endemic countries are required to complete a nine-month regimen of preventive therapy in order to obtain legal residency status. The fact that many latent TB cases are identified through immigration-related screening forges a link between TB control activities and those of the Immigration and Naturalization Service as well as immigration policy and narratives of discrimination. Haitians who apply for refugee status are referred to the Refugee Clinic, where they are screened for latent and active TB infection. Most test positive for latent TB infection (LTBI), because about two-thirds of Haitian nationals have been exposed to the infection at some point in their lives and therefore "carry the TB germ" (*gèm tebe*).

> "The stigma of being responsible of spreading HIV in the U.S. has marked Haitians with a 'stamp,' and those who have TB think that if they state it openly they will be given the responsibility of bringing TB in the U.S as well." (Focus group with community residents, Florida)
> "You know with the stigma that we have, what we were saying about the HIV and everything, and on top of that the color of our skin…In this country it is not very much respected…I think they're treated like a second-class citizen." (Interview with Haitian physician, Florida)
> "You must come [to the TB clinic]. Otherwise, you will have problems with immigration if your documents are not right." (Interview with TB patient, Florida)
> "Is latent TB infection a risk? Who knows! [The outreach worker] told me PPD is politic. They pay attention to a PPD positive according the region the patient comes from." (Participant observation field notes, Florida) [The PPD (Purified Protein Derivative) test is the skin test routinely used to screen for tuberculosis infection. It identifies persons with prior exposure to the infection (latent TB) who may be at risk for subsequently developing active disease.]

In summary, our ethnographic findings highlight commonalities between Haiti and the U.S. with regard to the association of TB with shame, social isolation, discrimination, concealment and HIV co-infection. However, in the U.S. the social contextual influences on

perceived stigma were more closely associated with the political aspects of Haitians being wrongly portrayed as sources of contagion, being the target of racism, and being unfairly treated through immigration policy. In contrast, the social context of TB stigma in Haiti underscores the disease's association with poverty, malnutrition and the loss of standing for families who are unable to keep their members healthy. In that context community narratives did not allude to minority or immigrant issues, political marginality, skin color or racism.

Degree and components of stigma compared across sites

Comparison of composite stigma scale scores across sites revealed very similar degrees of perceived stigma in the two community samples. The mean stigma score for the Florida Community sample was 62.4, and for the Haiti Community sample it was 61.0. These mean scores were not statistically different ($t = .59$; df $= 196$; $p = .557$).

In comparing the underlying components of stigma in the two settings, similar dimensions were found for three factors, and differences were found for three others. The common factors included internal shame, external problems and disclosure, and divergent factors included communicability, family reputation and other illness. For the Florida sample, EFA resulted in a four-factor stigma score. The four latent constructs in the model were labeled: 1) internal shame; 2) external problems; 3) disclosure; and 4) communicability. The four-factor model, presented in Table 4 explained 54% of the variance in stigma scores.

For the Haitian Community sample, a five factor solution provided the best fit for the data. The five latent constructs in the model were labeled: 1) disclosure; 2) internal shame; 3) external problems; 4) family reputation; and 5) other illness. The five factor model, presented in Table 5, explained 61% of the variance in stigma scores.

Table 4
Four factor model for stigma components – Florida community sample.

	Variance			
Factor	Eigenvalue	Explained	Items	Item-factor loadings
1. Internal shame	5.7	.27	Think less of self	.56
			Feel ashamed	.63
			Hide from others	.63
			Worry about sanatorium	.61
			Problems for children	.64
			Embarrassing because Haitian	.82
			Think worse because Haitian	.74
2. External problems	2.2	.10	Problems at work	.59
			Difficulty marrying	.55
			Loss of respect	.76
			Less respect for family	.72
			Others hurtful	.65
3. Disclosure	2.4	.12	Disclose to family	.62
			Disclose to friends	.34
			Disclose to neighbors	.72
			Disclose to church members	.71
			Disclose to co-workers	.68
4. Communicability	1.8	.07	Others avoid	.79
			Others refuse to visit	.60
			Assume has other conditions	.45
			Assume has HIV	.73

Table 5
Five factor model for stigma components – Haiti community sample.

	Variance			
Factor	Eigenvalue	Explained	Items	Item-factor loadings
1. Disclosure	5.1	.26	Disclose to family	.71
			Disclosure to friends	.81
			Disclosure to neighbors	.74
			Disclosure to co-workers	.83
			Disclosure to church members	.79
2. Internal shame	2.5	.13	Think less of self	.66
			Feel ashamed	.62
			Others hurtful	.62
			Hide from others	.71
			Others refuse to visit	.45
			Worry about sanatorium	.67
3. External problems	1.7	.08	Problems at work	.62
			Difficulty marrying	.61
			Others avoid	.59
			Think dangerous	.71
4. Family reputation	1.5	.08	Loss of respect	.69
			Less respect for family	.83
			Problems for children	.60
5. Other illness	1.4	.07	Assume has other conditions	.83
			Assume has HIV	.87

In the U.S. the most prominent factor was Internal Shame, accounting for 27% of the variance in scores. Particularly noteworthy is fact that the two items related to Haitian identity ("Embarrassing because Haitian" and "Think worse because Haitian") were two items most strongly correlated with this factor (.82 and .74). Other items loading on this factor were "Think less of self," "Feel ashamed," "Hide from others," "Worry about sanatorium" and "Problems for children." The loading of these items on this factor indicate a relationship between Haitian identity, internal shame, concealment, threat of incarceration and concern for children. The second factor, which accounted for 10% of the variance, was labeled External Problems because it grouped together items related to having problems at work, difficulty marrying, loss of respect for oneself and one's family, and others being hurtful. The third factor, accounting for 9% of the variance, grouped together items related to disclosure of one's diagnosis to significant others. These second and third factors were also found in the Haitian community sample. However, the fourth factor, Communicability (7% variance explained), was distinct to Florida, and it grouped items related to avoidance by others, others refusing to visit, and people making assumptions about the person having other illnesses and HIV.

In the Haitian Community sample, the most prominent component grouped together items related to disclosure of one's diagnosis, and this factor accounted for 26% of the variance in scores. In addition to this factor and the other one shared with the U.S., External Problems, the Haitian sample had two distinct stigma components: Family Reputation and Other Illness. Family Reputation included items related to loss of respect for oneself and one's children and problems encountered by one's children, and accounted for 8% of the variance. As in Florida, External Problems involved problems at work and difficulty marrying, but in Haiti it also included avoidance and being considered dangerous by others, and it accounted for 8% of the variance. Finally, the fifth factor, Other Illness, included the items related to the attribution of other illnesses as well as HIV co-infection, and accounted for 7% of the variance.

Discussion

Our findings highlight the ways in which structural influences shape the meaning of illness-related stigma. By comparing a single ethnic group living in two very different sociocultural contexts, we were able to show empirically the effects of social structure on tuberculosis-related stigma. In particular, the contrasting political-economic contexts found in the U.S. and Haiti shaped the meaning of stigma in significant ways. For Haitians in the U.S., a distinctive component of the illness experience was the perception of stigma as embedded in social structural relations of discrimination and racism stemming from the group's social position and identity as a negatively stereotyped immigrant population (cf. Saint-Jean & Crandall, 2005). The fact of being a culturally-different, disadvantaged "minority group" within a larger dominant society leads to distinctive perceptions of the meaning and consequences for affected persons. While the shame and embarrassment of TB-related stigma in Haiti was primarily related to conditions of poverty, malnutrition and HIV co-infection, in the U.S. stigma was interconnected with immigration policy and perceptions of being treated "differently" than other minority groups.

Even conducting the research study itself may have contributed to reinforcing images of Haitians as "unhealthy," associated with "stigma" and a "contagious" threat to the community. Sending out teams of interviewers into the Haitian community of South Florida to ask people about tuberculosis had the unfortunate effect of reinforcing the stereotype of Haitians as purveyors of infectious disease. Efforts to recruit study participants were not always welcome, and some questioned why an outsider was coming into their community and talking to everyone about T.B. Moreover, publishing articles and giving presentations on the study at professional meetings may itself reinforce within the scientific community the image of Haitians as a special risk group for infectious diseases. However, even more importantly our research contributes to better understanding of structural sources of stigma, and sharing this knowledge has the potential to influence positive institutional change (Weiss, Ramakrishna, & Somma, 2006).

In Haiti, the most important underlying component of stigma involved the sensitive issue of disclosing/concealing one's diagnosis from others. Our ethnographic data support the importance accorded to the decision to selectively reveal the condition to a limited number of trusted others. Study participants reported that sometimes people even hide their diagnoses from their own families, and are usually reluctant to disclose to people outside the home. Although a recurrent theme in Haitian narratives was the fact that TB was no longer the dreaded, stigmatized condition it once was (see Wiese, 1974), nevertheless people still conceal the condition for many reasons. It may reflect badly on one's social standing, some associates may avoid contact, and perhaps most significantly, it may lead others to assume that the real cause of the condition is being HIV positive.

In addition to the salience of minority group identity in shaping the meaning of stigma in the U.S., our findings document the impact of the organization of services on stigma experience in both countries. Tuberculosis treatment is largely confined to public sector care, which in itself is perceived as less desirable than private sector care and bears a certain level of stigma. Moreover, the threat of incarceration and loss of freedom for not following the rules contributes to heightened anxiety about the disease. Unfavorable media attention related to TB likewise plays a role in the social construction of stigma.

Our findings document the impact of structural forces through processes such as the organization of services, lack of protection of confidentiality, targeting of programs to high risk groups that are already stigmatized, media images and reporting, and government policies that discriminate or reinforce negative stereotypes. Conducting research on stigmatized diseases contributes to this process at the same time as it helps to mitigate the problem.

Methodologically, our findings underscore the importance of examining both the *degree* and the *content* of health-related stigma in comparative studies (Van Brankel, 2006). Very similar degrees of overall perceived stigma may obscure important variation in its meaning and underlying components. Such variation in meaning and salience, in turn, has implications not only for theory but for designing stigma-reduction interventions (Heijnders & Van Der Meij, 2006).

At a more general level, our findings suggest the value of incorporating a transnational approach to the study of illness domains. In our study a transnational framework was particularly useful in highlighting the structural underpinnings of social stigma affecting a marginalized immigrant group in the U.S. Moreover, given the nature of contemporary epidemiology of TB in industrial countries, comparative study of illness stigma and other social processes in both sending and receiving countries offer fruitful arenas for investigation.

Future studies might explore further the intersection of social identity and stigma processes through comparative research designs (Brodwin, 2004; Brown, 2000; Glick Schiller, çağlar, Guldbrandsen, 2006). As tuberculosis control is increasingly a global challenge (WHO, 2008), a better understanding of the problem as it affects immigrant populations should take into consideration the sociocultural contexts of both the country of origin and the host country.

The study findings point to the need to address stigma-reduction strategies at the institutional, governmental and structural levels (Heijnders & Van Der Meij, 2006). This includes improvements in the organization of tuberculosis control activities to protect patient rights to confidentiality of care, and attention to media reporting to the public. In addition, there is a need to address community concerns such as social isolation, discrimination, and negative stereotyping. A better understanding of the institutions that influence the social production of stigma, including the media, public health services, workplaces, immigration regulations and related government programs, is necessary to inform culturally competent services. Greater public awareness of the social forces that shape community perceptions of disease-related stigma is an important step in the larger endeavor of reducing harmful societal reactions to stigmatized conditions.

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