

## Stigma and Tuberculosis among Haitian Populations

Dr. Jeannine Coreil, Chair of Community and Family Health at USF, has been working with Hôpital Ste. Croix in Haiti for the past ten years on cultural factors and infectious diseases. Currently, their research is exploring the stigma surrounding tuberculosis. Unfortunately, stigma undermines progress in controlling the disease and in reducing TB's disabling impact on those suffering. This most recent research is funded by the National Institutes of Health, Fogarty International Center for \$725,698 for four years to June, 2007.

Tuberculosis is a public health problem of global magnitude-- 1,693,000 deaths in 2004 and 8,918,000 new cases worldwide, according to the World Health Organization. In the U.S. its victims are primarily the poor, immigrants and persons with AIDS. Efforts to control the disease have been severely handicapped by the effects of social stigma, ("I don't want to be labelled!") and further compounded by issues of race, social class, ethnic stereotypes, immigrant status and HIV coinfection. In this study Dr. Coreil is investigating the social dynamics of stigma in populations particularly affected by all of these issues— Haitians in the US and in Haiti. According to Dr. Coreil, the rate among Haitians is 120 active tuberculosis in Florida and 350 in Haiti/100,000.



Dr. Coreil with the Haiti TB Project Team

The study is also comparing the effects of the two countries' political-economic context on TB stigma. As Dr. Coreil states, "Social context is key to understanding how stigma works, and therefore how you, as a health provider, deal with the disease and the people." So far, the findings are revealing a stark reality—Haitians coming to Florida are wary of TB testing, because they feel labelled as TB immigrants. The label and stigma can yield policies and a culture unwelcoming to immigrants because of this disease risk. As one immigrant stated, "...*depi l gen yon maladi li pè di, li pè pou lòt moun pa konnen li,*



At Hôpital Ste. Croix, Haiti

*paske pou yo pa di se Ayiti, se Ayiti ki vin ak maladi a . Depi yo te fin di Ayiti, maladi sida se Ayiti li soti a. Dapre mwen sa vin enfekte eta Ayisyen tou le l vin gen yon maladi."* (When [a Haitian] gets sick, he is afraid to disclose it. He doesn't want others to find out and blame it on Haiti, that all these diseases come from Haiti. Ever since they said AIDS came from Haiti, in my opinion this has affected the Haitian mentality, every time someone gets sick)

In Haiti, the response is more economic, in that those with the disease feel labelled as poor. One Haitian commented, "*Wi sa fe fanmi an depanse lajan, si-l pa gen ase lajan, malad la pap trete, l'ap mouri.*" (Yes, it [the illness] requires the

family to spend a lot of money. If they have no money, the sick person will not receive treatment, and they will die.) In fact, the poorest are most vulnerable to the disease, given such factors as malnutrition, limited housing and income for necessary medications.

The study looks at institutional practices surrounding TB services—how these services are publicized, organized, and delivered, and the patients experiences with these. Unfortunately "structural stigma" (how such services operate) can unintentionally reinforce stigma that in turn

prevents patients from facing their disease and following the rigid medication regimen required. Therefore, the results of the study will help gain an understanding of the role of this social context on stigma, and will help improve how clinics manage illness.

**Latent Tuberculosis** This study is also finding the differences in the stigma for those with the active disease compared to latent infection (a major problem), and will measure how stigma impacts people practicing preventive measures. At this point, very little is known about their adherence to preventive therapy for TB, since those afflicted do not experience any symptoms. It is only through testing (via employment or immigration) that such cases become known. And unfortunately, there is a lot less motivation to take medication daily, methodically for months when there are no symptoms, and there are many other demands on time and money.

Dr. Coreil is using cultural epidemiology in an interactive quantitative-qualitative approach to help measure illness concepts and behavior. This approach combines the strengths of ethnography with traditional epidemiologic research. Her team has conducted an ethnography of TB stigma, beginning a cross-cultural epidemiologic study and a community trial of adherence to preventive therapy. They are focussing their study in Broward and Palm Beach Counties, Florida and Leogane, Haiti. The methodology has been tested and refined in a broad range of geographic settings and illness problems, including tuberculosis. Parallel cultural epidemiologic studies of illness-related stigma are underway in several other countries. Dr. Coreil states, “This will provide a great opportunity to integrate the Haitian study with a larger, multi-country collaboration. “

**Vicious circle** Dr. Coreil commented on a number of research dilemmas facing the team—one Catch 22 is that as they are researching the social stigma of TB, this can unfortunately have the effect of reinforcing the sense that something is “wrong” about having TB. “The challenge is to meet the needs of those with TB without reinforcing the stereotype and stigma,” she explained. In addition, by targeting Haitians in this study, the team runs the risk of reinforcing the image that Haitians are high risk groups, and that Americans might increase their fear of immigration. She is very sensitive to these dilemmas and the team has worked hard to avoid unnecessarily adding to the problem of stigmatization.

Another problem has been the scale of Haiti’s socio-economic and political problems. “The challenges are almost insurmountable to do this research,” she commented, given the US State department advisory against travel there. The needs in Haiti are so drastic, “it is hard to justify doing research that can help in the long term when the absolute poverty and upheaval are so blatant,” she added. Still, by breaking through the potency of stigma, she may provide the key to reversing the mounting TB statistics/trend, by helping the victims get the treatment they need without fear.



program in other areas.

Dr. Coreil, who grew up in Louisiana, has been working in Haiti for the last 30 years on projects related to maternal and child health, HIV/AIDS, and tropical diseases. Her Louisiana French background helped her to learn Haitian Creole, “While the past three decades of work in Haiti has been immensely rewarding,” she said, “the current challenges of implementing controlled studies in that setting are almost insurmountable.” After completing the stigma study, she plans to focus her research