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Cultural Feasibility Assessment of Tuberculosis Prevention Among Persons of Haitian Origin in South Florida

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A cultural feasibility study was conducted among persons of Haitian origin in South Florida to identify factors which might influence utilization of screening and treatment services for latent tuberculosis infection in this population. Five focus group interviews conducted among men and women explored cultural beliefs and practices related to TB, barriers and incentives to screening, and approaches to increasing treatment adherence. Key findings include the influence of social stigma and fears related to confidentiality of medical status as disincentives to screening. Cultural sensitivity to being labeled as a high risk group for these infections also emerged as a critical variable. Community-based approaches to health education for this population are described. Study recommendations include the planning of programs based on a service delivery model that stresses respect and personal attention to clients, improved interpersonal skills of health center staff, and coordination of services between private doctors and public health agencies.

KEY WORDS: tuberculosis; Haitians; stigma; screening.

BACKGROUND

Tuberculosis (TB) is a public health problem of global magnitude, affecting rich and poor countries alike. Its victims are the most vulnerable and socially marginalized groups within society: the poor, foreign immigrants, and persons with AIDS. Efforts to control the disease are severely handicapped by the pernicious effects of social stigma, which thwarts effective illness management. In the case of tuberculosis, the insidious effects of stigma are compounded by issues of race, social class, ethnic stereotypes, immigrant status, and HIV coinfection. All of these issues are set in bold relief when one examines tuberculosis among Haitians in the United States.

Like HIV/AIDS, with which it is closely associated, the resurgence of tuberculosis has become a global health emergency. There are close to 2 billion people currently infected with *Mycobacterium tuberculosis*, or one third of the world's population. Arising from this pool of infected people each year, there are about 8 million new cases of active TB and about 2 million of these individuals will die as a direct result of the disease (1–2). The global case fatality rate is about 23%, and in areas with high HIV rates it exceeds 50%. Among women of reproductive age, TB is the leading cause of maternal mortality (3). Like other Caribbean countries, Haiti has high rates of TB and HIV as well as coinfection. The incidence of TB in Haiti is the highest in the Western hemisphere and has long been recognized as one of the leading causes of death in Haiti, well before the arrival of HIV onto the scene. In 2000 the estimated TB prevalence rate was 350 per 100,000 population, and the estimated incidence rate was 147 per 100,000 population (4).

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Tuberculosis rates are also high among Haitian immigrants to the United States. Between 1993 and 1998, the case rate for active tuberculosis among Haitians living in the United States was 118.5 per 100,000 persons per year (5). In Florida, Haiti is the most common birth country (34.3%) among immigrants diagnosed with TB (5). Haitians make up only 2% of the state's population, but account for 15% of all active cases of TB, and this proportion is increasing (6). A retrospective chart and database review was conducted in 2000 among 142 reported cases of TB in Haitians living in Florida. The results gave a snapshot of an almost unrestrained epidemic of HIV coinfection and delayed treatment. Among 126 TB cases where HIV status was known, 77 (61%) were seropositive for HIV; among males in the high-risk age group of 15–44 years, 41 out of 54 (76%) were positive (7). The high coinfection rate among Haitian immigrants contrasts with other immigrant groups in the United States; less than 10% of the foreign born diagnosed with TB are coinfected with HIV (5). Adherence to preventive therapy for latent TB infection (LTBI) is also a significant problem in the Haitian immigrant population; only 38% of Haitian LTBI patients complete treatment, compared to 60% of the total population (7). High default rates in TB treatment contribute significantly to the emergence of drug-resistant strains of the disease.

There are approximately 250,000 people of Haitian descent living in Florida. Most are concentrated in the southern counties of Broward, Dade, and Palm Beach. Many of these individuals are recent arrivals (within the last 5 years) who keep close ties to their homeland. Despite the successful assimilation of thousands of Haitians into the mainstream, many more thousands live in poverty with little access to basic care and even less preventive care. In addition, although Haitians living in Florida have more opportunities than their counterparts who remain in Haiti, stigmatization and racism in this country impose a heavy social burden that increases marginalization and negatively affects the delivery and utilization of health services.

In 1989 the Advisory Council for the Elimination of Tuberculosis (ACET) set a goal for eliminating TB in the United States by 2010 (8). The definition of elimination was less than one new case per million population per year, although the nation's health objectives outlined in *Healthy People 2010* (9) subsequently set a goal of one new case per 100,000 population. A decade following the ACET report the Centers for Disease Control and Prevention (CDC) commissioned the Institute of Medicine (IOM) to review the lessons learned from previous years of neglect in TB control, and to address the continued appropriateness of the elimination goals. In its 2000 report, *Ending Neglect: The Elimination of Tuberculosis from the United States* (10), the IOM reaffirmed the commitment to the ACET elimination goal and made recommendations for how to achieve it. Among those recommendations was to accelerate the rate of decline of tuberculosis by increasing efforts at targeted testing and treatment of LTBI, particularly among high-risk individuals who do not access conventional treatment venues. In addition, the CDC has issued recommendations for addressing some of the discrepancies in access to preventive services noted in some foreign born populations (11). These guidelines advocate developing "profiles" of the epidemic in specific populations to define the epidemic more clearly and inform more directed interventions.

A cultural feasibility study is a type of assessment that investigates scientific as well as ethical, behavioral, and social issues in the design of interventions (12). In 2001 the authors conducted a cultural feasibility study of tuberculosis among Haitian-origin adults residing in Broward County, Florida (13). Funded by the Florida Bureau of Tuberculosis and Refugee Health, the goals of the study were to: 1) Explore cultural beliefs and practices related to tuberculosis and HIV screening among Haitians residing in Broward County (this county was selected because of its large Haitian population); 2) Identify specific incentives and barriers for increasing use of TB/HIV screening services; 3) Identify factors which influence adherence with treatment for latent TB; and 4) Make recommendations for appropriate interventions to achieve goals of increased screening and treatment adherence. This paper presents the findings and recommendations from the same study.

METHODS

Five focus group discussions were conducted during June of 2001 among Haitians residing in Broward County. Groups were stratified by age and sex (young men, older men, young women, older women) and included one group of young men dually infected with HIV and TB. Participants were recruited from the client population of Broward County Health Department, local churches and community centers, and personal networks of health department staff. Two groups met in the offices of the American Lung

Association, and three groups met in a local Haitian church. A native Creole speaker with experience in moderating focus groups led the discussions.

A semistructured discussion guide was developed based on the study objectives, current literature, and consultation with staff from the Bureau of Tuberculosis and Refugee Health. Discussions were tape recorded for later analysis. The moderator and the research team conducted debriefing sessions together shortly after each discussion, going over key points and clarifying the content of statements made by participants. Detailed notes were taken from the audiotapes and analyzed for content themes, recurrent ideas, and key points. Selective direct quotes were extracted from the discussion to illustrate viewpoints. Exact quotes are put in double quotation marks; paraphrased statements are indicated by single quotation marks.

RESULTS

Cultural Beliefs and Practices Related to Tuberculosis and HIV Screening

Local beliefs about the causes of tuberculosis included rapid chilling of the body, physical or psychological stress, and sorcery. Mystical involvement may be suspected if someone 'continually has the symptoms of a cold but can't find any cause for it.' The dominant perceived symptom of tuberculosis is coughing. As one participant noted, "Some people think every illness has a 'sign' (mak). With TB, it's coughing. And the body goes from very hot to cold." One man knew another man who suspected he had TB because of coughing, and he sought testing. However, some participants also believed that one "can get [tuberculosis] in other parts of the body, like the skin and bones." Perceptions of the degree of severity posed by tuberculosis were mixed. Some participants described local views of the illness as "not serious," while others noted its severity and danger. Many agreed with a woman who stated "It's not considered a serious illness. Especially here in the United States. But "in Haiti, it is much more serious." Respondents reported that in that country, "they keep people in a separate house, and don't eat with them." The reasons for the perceptions of decreased severity of the disease in the United States related to the more successful treatment outcomes observed in this country compared to Haiti. Also, the overall lower prevalence of the disease in the United States probably contributes to less perceived severity.

In their discussions about tuberculosis and HIV, participants expressed considerable sensitivity to the notion of Haitians being labeled as a "risk group." They noted the stigma that resulted from unfair publicity in the media about "Haitians and AIDS." Participants believe that Haitians do have a higher rate of HIV, but that this has been blown out of proportion and overemphasized. Sometimes Haitians get angry if a TB test is given to them because they feel they are being singled out as Haitian. This heightened sensitivity to illness labeling and stigma undoubtedly influences the high-level of concern voiced about patient confidentiality in clinical settings, discussed further in subsequent sections.

Most participants seemed to recognize that 'someone can have TB and HIV at the same time.' Often the first symptom of HIV is TB, people noted. Like tuberculosis, HIV is thought to have both natural and supernatural etiology. "Some people have a supernatural illness. Not the real illness." People suspect this, for example, if the spouse of an infected person does not get sick. Alternatively, if someone has the symptoms but the doctor's test shows negative, that's an indication it may be supernatural. If the doctor can't find what's wrong, the person may seek out a houngan (spiritual healer) in the United States. The consequences of someone having a supernatural illness, either HIV or TB, include less discrimination because the disease is not believed to be contagious. There may be sympathy or suspicion because the person has been targeted for a malevolent act, but the social consequences vis-à-vis family and community are less than in the case of a perceived communicable disease.

When questioned about local understanding of latent infection with tuberculosis, participants agreed that most Haitians in their community do not recognize the distinction between "carrying the germ" and "having the illness." They say "infection is the little brother of the illness." A healthy seeming person, participants agreed, won't believe the results of a positive test. "He knows he has it, but he doesn't believe it." Discussion revealed some confusion regarding the relationship between childhood vaccination with BCG, which most Haitians born in Haiti received, and screening test results. People vaccinated as children, it is believed, "will always test positive, but they are not sick." Even some local doctors say this, according to participants. This was corroborated by a follow-up study of local health care providers (14).

Similar skepticism surrounded the notion of asymptomatic HIV infection. Participants said that

local Haitians 'do not recognize the difference for HIV' either. Only if the sick person begins to see signs that the illness has progressed, then he or she may go for treatment. Of the groups interviewed, younger men demonstrated the most accurate understanding of the difference between infection and illness.

Participants were very vocal about the negative reaction of family members to someone's diagnosis with TB: "They don't speak to you;" "They humiliate you;" "They don't let you enter the house;" "They don't serve you coffee;" "They're even afraid to sit next to you." One man had a sister who owned a house with four apartments; she refused to let him live in one of them. Fear of contagion was the main concern underlying such reactions. However, participants also noted that some relatives accept the illness more than others. Friends have the same reaction as the family, participants agreed. 'Others are afraid of contact with the sick person.' 'The community treats the TB patient in a humiliating way. It keeps him apart.'

Incentives and Barriers for Increasing Use of TB/HIV Screening Services

Many participants expressed the view that local Haitians don't know where to go for screening services, including TB and HIV screening. In particular, people are not aware that there are free treatment services for these illnesses. Participants estimated that about 20% know about such services, but most people do not. People also face barriers accessing health department services, such as transportation problems, long waiting time, and language difficulties. Others noted that some are refused service because they lack health insurance. Several participants stated that people will avoid going to a clinic that is designated for TB or HIV patients, because of the stigma associated with these illnesses. When asked where people can go for TB testing, participants most often identified a private doctor's office. But it's difficult to get private care without insurance, people said.

Another recurrent theme in discussions of HIV screening was the belief that people avoid getting tested for HIV because they fear getting the results. They delay seeking care because of fears about the consequences of a positive diagnosis. "Many people avoid any tests because they think it's better not to know; they can live at ease without knowing." 'Because to know is to feel 'dominated' by it. No one wants to get positive results.' The fear is like that of "being marked."

When probed about fear of immigration problems, participants responded affirmatively. One man noted that long ago, doctors were required to send HIV test results to the Immigration and Naturalization Service (INS), and this would result in the person's deportation. Participants agreed that this was no longer done, but they believe that some people still fear it. People without papers and residency are also afraid to seek treatment after diagnosis.

Another source of fear about testing mentioned often was 'fear of others finding out.' Numerous stories of patients' exposure or disclosure of their HIV status and its consequences were recounted. This narrative was closely linked in several stories to the experience of being identified as an HIV patient through the process of receiving health services, in both public and private settings.

> A young man, for example, who is well known in the community, if he is seen in the HIV clinic, people know why he's there.
> If someone goes to a clinic and tests positive, it can end up in the newspaper. [joking laughter]
> When people ask me why I went to the doctor, I have to make up something else.

In discussions on this topic, a recurrent theme was the fear of loss of privacy in clinical settings because of the presence of Haitian staff. This is more often the situation in public clinics than private medical settings. In particular, participants noted that it is the lower paid clinic staff, who are more likely to be Haitian and part of the same community. Support staff have access to patient files. When probed about the expectation of patient confidentiality, respondents explained that unlike doctors and nurses, clerical and paraprofessional employees are not constrained by the same level of professional ethics.

> A doctor knows it's his livelihood and he could risk having the clinic closed. Patients can also be identified by medicines prescribed. The staff should be better educated." "And they need an organized system to protect confidentiality.

Because of such exposure fears, local Haitians were described as feeling more at ease in a mixed clinic than a specialty clinic. This preference applied to both HIV and TB clinics. Participants agreed that people in their community felt most protected from invasions of privacy at a private doctor's office. 'People will choose a private doctor, even if they have to pay more, because they believe it will be kept secret. Public clinics are less secret.' 'Haitians feel more at ease with doctors than other staff; when the nurse

asks questions before the doctor, the patient doesn't feel comfortable talking about it.'

> If it's an HIV clinic, other Haitians in the clinic will
> take notice of who is there.
> It needs to be a private place.

Another recurrent theme was the view that at the public clinics, Haitians are not received well. Participants didn't know of any clinics specifically welcoming to Haitians. They noted that the clinics have no translators for Creole speakers, while translators are provided for other languages and nationalities. Sometimes even with an appointment you don't see the doctor.

Factors That Influence Adherence to Treatment for Latent Tuberculosis

When asked about the importance of someone following prescribed treatment, most participants said you must see a doctor. However, the discussion did not make a distinction between latent TB infection and treatment of active cases. For example, some participants voiced the opinion that a sick person 'shouldn't even go to work. He should stay at home.' When probed specifically about preventive therapy, some participants felt people would accept the treatment with a good explanation, while others voiced skepticism. Many respondents identified the long duration of treatment (6 months) as an important barrier to preventive treatment. Another common view was that *some* people wouldn't want to comply with treatment because they think it's only the BCG vaccine causing them to test positive. "Some people go to the doctor, and the doctor tells them they have [TB], and they swear at the doctor, thinking he doesn't know [what he's talking about]." In addition, the possibility of having to name contacts was mentioned as a potential barrier to seeking treatment.

Suggestions for increasing adherence to preventive and therapeutic regimens focused on interpersonal relations in the medical encounter. Several respondents mentioned directly observed therapy (DOT), described as "a system to make people take the medicine in front of them" and "someone to encourage the patient to complete treatment, someone who keeps in contact." Many participants across groups also emphasized the need for health care providers who are sensitive, caring, and form personal relationships. Someone who will "take you from far and bring you in close (Pran ou lwen pou vinn pre)." The latter expression was imbedded in the discourse of several group discussions about health service needs. The phrase encompasses a multifaceted approach to patient care centered on close, personal relationships and attention to emotional/spiritual issues. This theme is discussed further in connection with strategies for improving services, addressed in the following section.

Appropriate Interventions to Increase Preventive Behavior

Initial response to questions about appropriate interventions to increase screening was sometimes along the lines of "It's difficult to think of ways to encourage more [testing]." Further probing elicited very specific recommendations regarding effective spokespersons, communication media, activities, and strategies. Preferred spokespersons included health professionals, local leaders, someone with the "gift of speech," teachers, clergy, entertainers, and athletes. There was agreement that Haitian radio stations were the media of choice for disseminating information. Also, involvement of local churches was strongly recommended.

Most participants expressed some dissatisfaction with TB and HIV services available in the community. They noted the lack of involvement of Haitian physicians in public health clinics, and would like to see more upper level Creole-speaking staff. One group discussed the need for a Haitian Health Center. Many patients are said to feel more "at ease with Haitians." Nevertheless, as noted before, patients are reluctant to be assisted by Haitians in the capacity of licensed practical nurses (LPNs), secretaries, and others whose jobs are considered less influenced by principles of confidentiality. Also noted previously was the desire for personal attention in patient relations. A "one-on-one" (a nou de) approach was mentioned several times. An approach that treats people gently, with respect and courtesy, and provides "good customer service."

A variety of possible motivational events for increasing awareness of TB and HIV services were explored with the focus groups. Participants were enthusiastic about a community fair or recreational event, focused on family fun, with speakers, music, and entertainment. One participant used the expression "It takes syrup to attract ants" to describe such an event. Other kinds of suggested activities included spots on TV programs, church-sponsored events, conferences,

seminars, meetings, and posters. Worksites such as factories that employ large numbers of Haitians were mentioned. To attract the target population, the event should be directed to the Haitian community, not to the community at large. However, the event should not be billed as a TB or AIDS event.

IMPLICATIONS AND CONCLUSIONS

Study findings point to the need for greater awareness within the Haitian community about tuberculosis and services available for its control. Our results suggest that only a minority of the population understands the distinction between latent TB infection and active disease, and most do not know where to go for free testing. Similarly, the distinction between HIV infection and AIDS is not widely understood, and awareness of HIV services is limited. System barriers and personal fears impede the seeking of testing for both diseases, and most of those affected delay seeking care until the appearance of symptoms. Fear of social isolation, rejection by family members and exposure through health service utilization inhibit use of testing. Better understanding of the effects of the BCG vaccine on adult TB screening is needed. Misinformation on this subject may extend to the local Haitian medical community.

The community appears eager to see more health outreach programs made available to the Haitian population. Several components of outreach were supported in the discussions, including a “customer friendly” clinic program, home visits of health workers, encouragement from a “sponsor,” and community education through radio, churches, and fairs. Desirable spokespersons for TB and HIV educational messages include Haitian health care professionals, prominent individuals in the community who are HIV positive, and entertainment or sports celebrities.

One of the strongest themes expressed in the focus groups was the cultural preference for a “one on one” personalized approach to connect effectively with the Haitian community. Such an approach was described as one based on respect, consideration, sensitivity, and trust. Direct interpersonal relations seemed to be a key element. How such a personalized approach can be operationalized in clinical settings is a challenge, because although the participants favored services more “welcoming to Haitians,” including more bilingual–bicultural staff, the presence of some types of Haitian staff in clinical settings was clearly a barrier to testing. Fears regarding loss of confidentiality and resulting social stigma were described as inhibiting TB and HIV screening behavior. Strengthened safeguards regarding patient confidentiality were supported, including the elimination of specialty clinics for TB and HIV.

The design of health programs focused on TB and HIV in the Haitian American community must take into consideration the heightened sensitivity of this group to the history of social discrimination surrounding HIV and Haitians (15–17). Participants expressed concerns about the effects of an intervention that singles out the Haitian population as having special problems in this area. They favored a general approach that integrates TB and HIV information and services within a broader context of health needs. A community based TB/HIV intervention focused on the needs of all ethnic groups in the county would be favored over one focused exclusively on Haitians. Alternatively, a comprehensive health outreach to Haitians that incorporates TB and HIV with other health needs of the population would be acceptable.

A culturally sensitive intervention program should also take into consideration the existence of beliefs attributing supernatural etiology to both tuberculosis and HIV/AIDS. At the very least, health care providers should be aware of this belief and incorporate appropriate, nonjudgemental questions in their history taking to identify patients who might suspect mystical etiology. Since the same symptoms are attributed to both natural and supernatural TB, including weight loss, lack of appetite, low energy, and coughing, tangible evidence of diagnostic tests should be provided, especially in situations where the patient’s domestic partner has not been infected. It is likely that patients who suspect supernatural etiology for their conditions are at higher risk for dropout in treatment programs, since biomedical treatment is thought to be ineffective in such cases, therefore more focused retention efforts should be directed to such patients.

Our cultural feasibility study was useful in the subsequent development of a public–private partnership between the Broward County Health Department, the North Broward Hospital District, and a group of doctors affiliated with the South Florida Chapter of Haitian Physicians Abroad. A Haitian Community Clinic was established to provide general medical services in a neighborhood with a high proportion of Haitian residents. The county tuberculosis program and the Bureau of Tuberculosis and Refugee Health provide training, education, TB medication, and screening supplies to the clinic to

incorporate TB and HIV screening into the routine care provided to the patients.

To the extent that other immigrant populations share some of the same social and cultural experience of tuberculosis and HIV, the implications of the study may be relevant for designing control programs for other cultural groups (18–22). The themes of stigma and social isolation appear common in many geographic settings (23–26). Also, like ours, a number of studies advocate for a culturally sensitive approach to tuberculosis intervention (27), along with a service delivery model that stresses improved interpersonal skills of health center staff and coordination between private doctors and the health centers.

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