TB & CULTURAL COMPETENCY

Notes from the Field

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Brother to Brother

By Eric Lynch, Public Health Advisor

Introduction

TB prevalence rates in many Sub-Saharan countries are among the highest in the world. As a growing number of African immigrants are coming to the United States, either as refugees or as documented or undocumented immigrants, special attention must be given to the particular barriers these individuals face when utilizing health care services. The following case was seen in New York City, one of the most common entry points for immigrants, refugees, and visitors to the U.S.

The Patient

Mr. S.I. was a 33-year-old West-African from Mali, who presented at the emergency department of a municipal hospital with cough, significant weight loss, and other signs and symptoms of TB. He had been in the U.S. for only a year, entering on a tourist visa, but staying longer than allowed by working for a delivery service. Before getting sick with TB, he said his health history had been relatively normal. His original language was Wolof, but he also spoke limited French.

Diagnosis and Treatment

My case management area assignment had recently changed, and Mr. S.I. was one of my first case assignments. This turned out to be a lucky coincidence since I was the only French-speaking case manager in my area. Mr. S.I. was diagnosed with smear negative, culture positive pulmonary TB. His chest X-ray was abnormal, showing non-cavitary TB. During his two-week hospitalization, I visited him and explained that he had TB, educated him about the disease and its

treatment, and asked about contacts. Communication in French was manageable, but would have been better if a Wolof interpreter had been available. Unfortunately, we were not able to locate one. When Mr. S.I. was discharged, I took him over to the DOT clinic so he would know how to get there and to introduce him to the DOT staff. At first, I could tell gaining Mr. S.I.'s trust could be a challenge. He was somewhat reluctant to cooperate with my requests for information because he feared problems with his immigration status. I did my best to reassure Mr. S.I. that I was only interested in providing him with good treatment and preventing those close to him from getting sick, but concentrated my efforts on using

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our common language to simply connect with him. I used a more casual approach with him than I usually do with patients. I think this slow and easy approach helped to build trust. I was also able to help him navigate the health system, since he needed referrals to other doctors for unrelated health problems. HIV testing was offered as the "standard of care" and he agreed to have the test, which proved to be negative. Mr. S.I. was usually adherent to DOT and doctor's visits, but on some days he needed DOT at home when the weather was cold.

The Contact investigation

Phase 1: Initially, Mr. S.I. named only a handful of contacts, whom he called his "brothers," and with whom he shared his apartment. Over time, as a comfort level developed, he provided more names. The case was referred to a French-speaking disease control investigator for contact investigation. The apartment building where Mr. S.I. resided was situated on a corner with entrances on two streets, having two separate addresses. Later on, this made identifying who lived where quite a problem, as even people living in the same apartment could legitimately give different addresses. The disease control investigator made a point to talk with each contact privately, educating them patiently about TB and latent TB infection (LTBI), assuring them of confidentiality, and explaining the process of skin testing, medical evaluation, and treatment if needed.

Phase 2: The first round of testing showed that more than 50% of the contacts in the apartment were tuberculin skin test (TST) positive. Even though the contacts were all from areas of high TB prevalence, and therefore may not be recent converters, my supervisor became concerned about the need to expand the contact investigation. On one home visit, the DOT worker observed that people from another apartment down the hall frequently visited Mr. S.I.'s apartment, as if it were their own home. It turned out that these were more "brothers" from Mali, and that all of them spent time together in each other's apartments and at the same workplaces. Once the first contacts who tested positive had received good care at the hospital chest clinic, more contacts came forward on their own.

Phase 3: Another home visit late one afternoon found 19 people in Mr. S.I.'s apartment sharing a meal, served on big platters by a woman who lived nearby. Her 5-year-old child was also present. The DOT worker reached the conclusion that almost everyone was "exposed" because many people from adjacent apartments came by regularly to share meals and spend time together. My supervisor then decided to expand the investigation more aggressively, concluding that all members of this extended household network should be tested.

At first, some people were reluctant to have the TST because they were not sick and did not want to miss work. Many people had two or more jobs and complicated work schedules at delivery and taxi companies. To make the process more convenient, Saturday home sessions for testing were organized. Arrangements were also made for TST readings to occur at home the following Monday. Over time, these contacts became more familiar with me through the consistent home visits. They began to compare their health with that of Mr. S.I., and understood that I was only trying to protect their good health. Eventually, 22 contacts were identified, all related males between the ages of 18-45, as well as the cook and her 5-year-old son. Eighteen were evaluated, 12 (55%) were TST positive, 8 (67%) started and 5 (63%) completed treatment for latent TB infection (LTBI), including the 5-year-old.

Outcome and Summary

Treatment of case: Because so much time was invested gaining credibility and trust from the outset, treatment completion was relatively easy to achieve. Mr. S.I. completed his treatment in 6 months.

Contact investigation: Sometimes contact investigations can prove more complicated than treatment of the index case, as was true in this example of West African immigrants. There was confusion about correct addresses, the relationship between the index case and the contacts, and the number of persons who regularly spent time in the apartment. Since mealtimes were an important time for socializing, asking questions about who came to meals was an important way to identify people who were exposed to the index case. It turned out that all members of this extended family who were in the building at mealtimes congregated and ate together. Some contacts

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were not residents, relatives, or co-workers, but just people who showed up at mealtimes.

Treatment of LTBI: Expedited routine follow-up visits for LTBI patients facilitated acceptance of treatment in the case of these immigrant workers. Some of the identified contacts worked more than one job, and it was much easier to convince people to take LTBI treatment if they knew they could get back to work right away. Another important factor was cost of care. From the outset, this was a concern despite being assured that LTBI treatment is free. Again, once some of the first contacts received good care, free of charge, more contacts came forward for treatment. In addition, city subway and bus tickets were provided as enablers so that the contacts could attend monthly follow-up visits at no cost.

It was helpful that one of the contacts also spoke some English. Since gaining trust can sometimes be a challenge when working with immigrant groups, locating someone who can serve as a "cultural broker" can be valuable to the successful care of the patient. Cultural case management takes this idea a bit further (see Sub-Saharan African profile for more information). In this case, the English-speaking contact agreed to help us reassure people that accepting treatment would in no way affect their immigration status. He cited his own experience as an example that "nothing would go wrong."

Cultural broker: One who bridges, links or mediates between groups, or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change. (Jezewski & Sotnik, 2001)

Community-Based Organizations Serving African Immigrants

Community based organizations are often a useful resource for working successfully with immigrant groups. The following list represents organizations that we have worked with either directly or indirectly.

BOSTON

African Community Health Initiative
Multicultural AIDS Coalition, Inc.
Phone: 617-442-1622

NEW YORK

African Salvation Group Corp.
Phone: 866-280-3232
www.asgroup.org

African Services Committee, Inc.
Phone: 212-222-3882
www.africanservices.org

Center for Immigrant Health
Phone: 212-263-8783
www.med.nyu.edu/cih

Directory of NY Area African Immigrant Association
www.columbia.edu/~ljb34/forum/directory.pdf

MINNEAPOLIS / SAINT PAUL

African Assistance Program
Phone: 763-60-9643, 651-379-5234

Somali Education Center
Phone: 612-872-8812, 612-558-6316
www.someducenter.org

African Community Services
Phone: 612-721-998
www.africancs.org

African Development Center
Phone: 612-333-4772
www.adcminnesota.org/

African American Relief & Development Initiative
Phone: 612-766-9500
www.aradi.org

LOS ANGELES

African Community Resource Center
Phone: 213-637-1450
www.africancommunitycenter.org

SAN DIEGO

Alliance for African Assistance
Phone: 619-286-9052

SAN FRANCISCO

African Immigrant and Refugee Resource Center
Phone: 415-433-7300
www.ncccsf.org/airrc/

WASHINGTON, DC

African Immigrant and Refugee Foundation
Phone: 202-234-2473, 301-593-0241
www.airfound.org

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Cultural Profile: Sub-Saharan Africans

English-language academic literature does not offer an article which discusses TB treatment beliefs in a West-African country. Therefore, the section below is a general review of TB beliefs and treatment conditions related to African immigrants, acknowledging the commonality found among peoples in Sub-Saharan Africa. Sources for this review include articles listed at the end, along with the personal experiences of several contributors.

Beliefs about TB and its Transmission

Views among Africans about the cause of TB and how it is transmitted vary greatly. Many people are unclear about the nature of disease, a factor attributed to the breakdown of traditional medicine without suitable replacement by Western medicine. Some Africans certainly subscribe to current scientific knowledge about TB. However, compared to those in the developed world, Africans are more likely to attribute TB to supernatural forces. Some groups see TB in two forms: one disease caused by evil spirits which are sent by those who are jealous of the victim, and a second "Western" form of TB which is transmissible and is due to pollution, smoking, or excessive use of alcohol. TB is seen as punishment for breaking taboos, often around sexual behavior (e.g., not abstaining from sex after the death of a family member or having sex after a woman has had a spontaneous abortion). Others see poor working conditions as the cause for TB transmission.

TB instills great fear and stigmatization and a person who is diagnosed with TB may be seen as "bad" or "dirty." Many Africans believe that TB is transmitted through physical contact (e.g., sharing dishes, having sex, mother-to-child contact), leading to social and sometimes physical isolation. A person with the disease may be abandoned by his or her spouse, and those who are unmarried may see their chances of marriage dwindle to nothing. Several studies have noted that Africans may confuse health information about TB and HIV. Thus, some believe that TB is not curable and that it may be prevented through the use of condoms.

Family Structure

Immigrants from Africa may use the word "brother" or "sister" to describe any person with the same last name or even from the same country. This person could be a biological brother, uncle, sister, aunt, or cousin. Likewise, Africans may use "son" or "daughter" to describe people we might call nephew or niece, as well as sons or daughters. This can make identifying the relationship between contacts and the case a difficult puzzle to solve. This is often clear only by asking directly who are the father and mother of each person. Alternatively, one may decide that determining the nature and duration of exposure to the infectious case is more important than determining the exact family relationship.

TB Treatment in Africa

Much of Sub-Saharan Africa is beset by poverty as well as high TB rates. Particularly in rural areas, people may experience challenging work and living circumstances, struggling against a lack of basic services such as water and public transportation. Infectious TB patients may continue to share rooms with relatives or co-workers because of housing costs or a lack of alternatives. Public medical facilities are often understaffed and experience frequent shortages of drugs. Private doctors are viewed as more competent but impose fees that are out of reach for many patients. Many patients are non-adherent to treatment because drugs are not available or are too expensive. Because it is felt that Western medicine cannot control TB, some patients seek help from traditional healers and may be only partially adherent to medical regimens.

Some patients may believe that modern medicines can weaken your body. This may lead them to consider that avoiding taking medicines is healthy. They may fear getting dependent on medicines, getting weaker, or having to pay a lot for medications. Some may try modern medicines at the same time as they try traditional medicines.

Their experience with clinics and hospitals may vary, with some believing that you go to the hospital to die. Others may have experiences that convince them that diseases can be cured – so they would go to the hospital when they feel sick, but not when they do not feel sick. Many know that cough is a sign of TB, a serious disease that can lead to death. If they are prescribed medicines for a serious disease at a time when they feel sick, they are

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likely to be adherent to treatment. They can accept the idea that treatment should be long for such a serious, life-threatening disease. However, they may be skeptical of doctors who prescribe medicines in the absence of symptoms, as for the treatment (LTBI).

Barriers to Care Following Immigration to the U.S.

Several factors work against African immigrants receiving appropriate and timely TB care in the United States. Immigrants may not speak English well, may lack health insurance, and will be unfamiliar with the American health care system. TB clinics often lack interpreters, translated health education materials, and an understanding of African cultures. Because of the stigmatization of TB in Africa, individuals may avoid the clinic, fearing that they may run into someone they know. Adherence to treatment for LTBI may be poor because of beliefs about the protective effect of BCG vaccination and because of reluctance to take medicines in the absence of symptoms. On an organizational level, African patients are often combined with African-American patients when the two groups actually have very different characteristics and needs.

Recommendations

When working with immigrant groups, it is important to emphasize that having TB or LTBI will not lead to deportation. In some communities, it may be preferable to provide services around a variety of health concerns to avoid the stigmatization accompanying illnesses such as TB and HIV. One method for reaching immigrant populations that has proven effective is *cultural case management*, as described by Goldberg and colleagues. In this model, members of the target group are enlisted to serve as liaisons between that group and the TB clinic. These individuals should be trusted members of the community and may be paid or serve as volunteers. Their responsibilities include outreach, health education, adherence support, and interpretation.

Conclusion

Rather than taking a "cookbook" approach to learning about TB knowledge and attitudes in particular African groups, it is important to acknowledge that health beliefs vary greatly among African immigrants. As in the United States, health beliefs are affected by age, gender, education, socioeconomic status, family history and personal experience with a disease, and a number of other psychological factors. Larger differences may be found between individuals from urban environments and those from rural areas. When working with a patient who is an immigrant, it is important to inquire about his or her beliefs and to avoid making assumptions based on ethnicity or nationality.

Literature:

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   Why?_____

   _____

2. Was the newsletter's length: ❑ too long ❑ too short ❑ just right

3. Will you apply anything from this newsletter to your current practice? ❑ yes ❑ no

   If yes, what specifically _____

   _____

4. What **cultural competency** topics would you like to see in future newsletters:

   _____

   _____

We need cases to highlight!

Many of you are out in the field doing great work with people from a variety of cultural backgrounds.

Would you be willing to contribute a case study or article? If so, please provide your contact information. Fax this page to 973-972-1064

Many of the photos in this newsletter are courtesy of the Stop TB image library at: http://stoptblpipserver.com/

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