TB & CULTURAL COMPETENCY

Notes from the Field

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No Woman Is An Island

This case comes from a nurse in the northeastern region. It involved a patient whose care took place within a larger Haitian immigrant community.

Lisette was a young woman with a lot to look forward to. At age 23, she was engaged to be married and expecting her first child. After emigrating from her homeland of Haiti to Miami, Florida, she spent several years in a suburban northeastern town. Lisette began prenatal care at our county's public health comprehensive care center and received a tuberculin skin test. When she returned to have it read, she had a reaction that measured 22 millimeters and the staff sent her to get a chest X-ray. TB could not be ruled out from the X-ray. She was referred to the TB control staff for further evaluation; it was at this time that I first met her. I introduced myself and explained that we would do a further evaluation, including an interview about her medical history. During the interview she related that she had been exposed to TB both when she was a child and since she had come to the United States.

Lisette had been treated for a respiratory infection about the same time she realized she was pregnant. At the time, she still had a persistent cough, but she assured me that she was confident she did not have TB. She had seen people

with TB in her neighborhood on the outskirts of Port-au-Prince, and remembered them as frail and emaciated, too ill to work. In contrast, she felt generally healthy and worked every day as the bookkeeper for her mother's small business. However, the local doctor strongly suspected that she had TB and prescribed a standard four-drug regimen pending the results of laboratory tests. The doctor informed her that while it was not necessary to be hospitalized, it was essential that she avoid exposing others to TB by staying at home and avoiding close contact with others until test results showed that she was not infectious. She shared her house with a Haitian couple, but she had her own room and could have her meals apart from her housemates. We agreed that she would stay in the house and have us visit her for directly observed therapy (DOT). Since

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Women participate in a ceremony in Brooklyn, NY

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her fiancé worked several towns away and since her mother spent most of her time in Miami for business purposes, Lisette's housemates were her primary company and an important source of social support.

The final TB diagnosis was a shock to Lisette and she expressed anxiety about what it would mean for her pregnancy. I reassured her about the safety of TB medications and emphasized that treatment would ensure she would be healthy when the time came for her baby to be born. In my first few visits to provide DOT at her home, we talked about many things: baby names, her plans to expand her mother's business, job possibilities that her fiancé was pursuing, and what foods might allay the nausea she felt after taking her medications. Once the doctor determined that she was no longer infectious, her fiancé was a frequent visitor at the house and often accompanied Lisette to her clinic visits. Over time, I developed a good rapport with both of them and came to admire her strong work ethic, her conscientiousness when it came to her prenatal care, and her flair for home-making - her house was always extremely neat and carefully decorated. While I relied on an interpreter in our initial meetings at the clinic, Lisette's English improved every day, and at home visits, we communicated without interpreters.

We contacted our public health colleagues in the town where Lisette's fiancé worked and arranged for him to be tested for TB infection. She was very worried about his health and was relieved when his two skin tests were negative.

Based on our interviews with Lisette, we determined Lisette's housemates were her only other close contacts. The housemates, Cesaire and Irma, were also immigrants from Haiti, although they had been in the US longer than Lisette. They were long-time friends of her mother and came from her mother's neighborhood

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in Port-au-Prince. Lisette's mother had allowed Cesaire and Irma to stay in the house that she rented before Lisette arrived in the area. Lisette had moved in with them only a few months before she was diagnosed with TB. We told Cesaire and Irma that they would have to have a TST to detect TB infection and that we would

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test them three months later to see if they had been recently been exposed to TB. Irma's TST was positive, and after reading the result, I explained that the result did not mean she was sick, but that we would have to do more tests to determine next steps. She was evaluated by the doctor at our clinic who ruled out TB disease and started her on a regimen for LTBI.

Initially, I brought Irma's medications to the house during my regular DOT visits to Lisette. When Irma started treatment, I noticed that Cesaire's demeanor towards me and my coworkers who visited the house had changed. Initially he treated us with hospitality, and was rather friendly; later, he began to question our procedures in relation to his wife's treatment as well as Lisette's. We tried to address his concerns and answer his questions, but it was clear that he remained doubtful about the purpose of Irma's regimen and suspicious about Lisette's condition. Cesaire questioned the medications we brought for Lisette and seemed to want to review everything she took. He insisted on interpreting for us himself when we interacted with Irma, who spoke little English. We found ourselves asking questions and repeating key information in several different ways to ensure that our patients understood our messages and we understood their questions.

Tension in the house began to rise. The housemates were always pleasant and easygoing until Cesaire's second TST was placed and it was positive. We gave him an appointment for a chest X-ray, just as we had with Irma. A week later, Cesaire was waiting for us when we got to the house. As we walked in he waved a piece of paper at us, looking furious. Speaking rapidly and loudly, he said he had received notice that he had TB, and it was because of Lisette. He repeated again and again that he just received notice she had TB and that she had "contaminated" Irma and him.

We were stunned. It did not seem possible he had not understood Lisette's diagnosis until now. We were even more surprised when we examined the paper he held out to us. It was a notice from our clinic that his chest X-ray was normal and that he had a follow-up visits scheduled; it made no mention of any other patient. Even after we went over the form line by line with him, he insisted his wife's and Lisette's diagnoses were news to him.

While neither woman challenged him or contradicted anything he said, Lisette walked to the car with us when we left, and quietly told us she believed Cesaire wanted her to leave the house so he could take over the lease and not be dependent on her mother. She was also worried because he had told her aunt who lived nearby that Lisette was terribly sick and was causing sickness in others. She was afraid he would convince her family to send her to relatives in Miami or even back to Haiti until she was cured of TB. While Lisette was in many ways independent and self-reliant, she clearly did not want to directly confront Cesaire or argue with her aunt about her living situation. We took a collective deep breath. It was likely the clinic doctor would recommend that Cesaire start treatment for LTBI and we were not off to a promising start with him.

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When Cesaire started coming to the clinic regularly, he asserted his personality in the same domineering style he used at home. One several occasions, he misrepresented to one staff member what another had told him. We learned to convene and review with each other the information and directions we wanted to convey to him. Also, we learned not to rely on him for information about what our coworkers had told him.

At the same time, we realized that Cesaire was a force to be reckoned with in the Haitian immigrant community, which made up a significant proportion of our patient population. Some patients commented that in the poultry processing plant where he worked, Cesaire had considerable influence among Haitian employees. Others told us that he was a respected in the community as a spiritual counselor and practitioner of the Haitian religious tradition that fuses elements derived from traditional West African belief systems with Christian rites and symbols, commonly known Vodou in the US. Cesaire eventually confirmed this, explaining to one staff member that he came from a family of spiritual healers and that he upheld spiritual traditions in the US and on his visits back to his home in Haiti. Because his standing among a group of Haitian patients, we were sensitive to the possibility that gossip within that group could

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jeopardize our relationship with individual patients and even inhibit others from seeking care. We were careful to schedule Lisette's clinic appointments on different days than Cesaire's, and tried to minimize the time he was free to speak with other patients.

We could not stop Cesaire from talking outside the clinic, but we did discuss how we would respond if patients came to us repeating rumors or information they had heard from him. This turned out to be important. Over the course of a few weeks, we received requests for nutritional supplement drinks from several Haitian patients on LTBI treatment, some of whom were indignant that drinks had not been offered to them before. Eventually we learned from Lisette that Cesaire had noticed she received supplement drinks from us and cited his lack of them as evidence that we treated her better than we did Irma and him. After the first few patients asked for nutritional supplement drinks, we discussed the matter in a staff meeting. We agreed on how to educate patients about the appropriate use of nutritional supplements and their disadvantages for people who are not clinically underweight. We also brainstormed about what kinds of foods would minimize any side effects of LTBI medications; this would enable us to offer alternatives when we had to say no to nutritional supplements.

Given the tensions in her household, we were relieved when we learned that Lisette and her financé were moving to another part of the state. We transferred her care to the TB program in her new county, and noticed Cesaire became less confrontational once he and Irma were alone in the house. We never knew how much of his attitude towards us and the TB program was due to a real fear of TB in his household, and how much was a ruse intended to push Lisette out of the house. After Irma and Cesaire completed their treatment, we all congratulated ourselves on a job well done. To thank us for helping her through a rocky period, Lisette brought her new daughter by the clinic a few months afterward while visiting relatives in the area. She expressed that as we had reassured her at the beginning of her treatment, she and her daughter were healthy and off to a good start in their new home.

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Ceremony taking place Carrefour, Haiti

Lessons learned

- *Interactions with people who are important in patients' lives can be as critical to successful care as the patient-provider relationship.* We realized Cesaire's objections to our visits could make it practically impossible for us to effectively manage Lisette's case, no matter what her own feelings were. We had to develop strategies to interact effectively with Cesaire to ensure that Lisette and Irma, and eventually Cesaire himself, successfully completed treatment.
- *A unified message from the healthcare team can dispel doubts and distractions among patients.* In the case of Cesaire, it was critical that all staff gave the same consistent message about his care, as well as Irma's and Lisette's. We developed a team consensus on what was necessary for the care of each patient in Cesaire's household and reviewed what we needed to convey to each of them to ensure our message was consistent and comprehensive. With this unified message, we were able to deflect any of Cesaire's actions that might undermine trust in us and our procedures. At the same time we developed a working relationship with him that enabled us to provide him with care during his treatment.
- *Although LTBI is a much simpler condition to treat than TB disease, patients nonetheless need education about what it is and the rationale for its treatment.* Our Haitian patients were very familiar with TB: nearly all of them had known someone with the disease at some point in their lives. However, LTBI is not routinely diagnosed or treated in Haiti and Irma and Cesaire had never heard of it before they were diagnosed. It was necessary to address all aspects of immune response to infection, possibilities of developing disease from remote infection, and the effectiveness of treatment for LTBI, so that they fully understood the importance of completing their treatment.

Stigma and TB

"Stigma" refers to socio-cultural meaning given to conditions, attributes, or behavior, which defines individuals as inferior or socially unacceptable. Stigma is not limited to a specific action or part of a person. Rather, it extends to all aspects of the self and negatively impacts on an individual's social standing interactions and standing, inflicting damage on his or her identity. A person who is stigmatized may feel guilt, shame and isolation[1].

TB-related stigma has a long history, partly because TB flourishes in conditions of poverty and malnutrition. Families and close friends can be embarrassed if they know a person with TB disease because of the related stigma[2]. Coriel et al.'s recent study of TB-associated stigma among Haitians in the US and in Haiti highlights that TB stigma is dependent on the social, cultural, and political contexts in which the disease is diagnosed and treated[3]. In Haiti, TB is associated with poverty, malnutrition, and neglect. Coriel et al found that TB stigma in Haiti has declined with increased availability of treatment and reductions in related morbidity and mortality. In the United States, TB has come to be linked to foreign-born populations, including Haitian immigrants, resulting in a heightened perception of TB-related stigma among Haitians in the US as compared to Haiti[3].

In addition to its long association with impoverished and immigrant populations, TB in the US is also closely linked with HIV/AIDS. A person with TB may be presumed to also have HIV, a disease itself heavily laden with stigma. Many Haitians remember being collectively identified as carriers of HIV when the disease first emerged in the US, and may be particularly aware of the negative impact of association with HIV[4].

TB and LTBI patients reported to Coriel et al feeling targeted by media sources, public health workers, and immigration agencies as sources of TB transmission in the US. The association with TB increased their sense of being part of a marginalized group in US society, increased their perceived vulnerability to discrimination, and in particular raised fears that their immigration status would be imperiled by their diagnosis[3]. Coming in the midst of the multiple challenges of gaining an economic foothold in the US, establishing new relationships, and negotiating a social position in an unfamiliar culture, TB-related stigma may be a heavy burden for Haitian immigrants.

Spiritual Life and Healing in Haitian Communities

Haiti's Spiritual Traditions

The Haitian religious practice commonly referred to as *Vodou* is based on diverse spiritual traditions of enslaved Africans brought to the French Caribbean colony of Saint Domingue in the 16th and 17th centuries, melded with the French Catholic symbols, rites, and iconography of the colonialists[6]. The new world spiritual practices and beliefs were also shaped by the experiences of enslavement, enforced plantation labor, and a cataclysmic revolution that led to the establishment of an independent Republic of Haiti in 1804[7]. As it became established in the peasant settlements and extended family networks of the largely rural country, Vodou practice incorporated aspects of the island's geography, flora, and fauna in its pantheon of spirits and its practices[8].

The Vodou belief system describes complex networks of relationships linking together generations of family members, living and deceased, and linking humans to spirit entities. Haitian spirits form a complex hierarchy, extending from the ultimate creator identified as the Good Lord through hierarchies of spirits that are rooted in Haiti and tied to its history and its people. Vodou spirits have individual personalities and strengths that supplicants draw on in times of need, much as Catholic saints have specific arenas of authority[9]. Haitian spirits have individual histories that represent in mythologized form the history of Haiti, the country's African origins, and, more universal aspects of the human condition[5,10]. A main function of Vodou practice is to nourish and strengthen the connections between the spirits and human beings, and between living and ancestral realms. This is achieved partly through private and public ritual demonstrations of respect and appreciation for the spirits that create a welcoming space for direct communication with them[11,12].

Another important way to solidify ties between the material and spiritual worlds is through healing. Vodou ceremonies mix the sacred, in which spirits are honored and ritual observed, with the practical, in which everyday problems like financial setbacks, thwarted love, or rebellious children are addressed by the spirits speaking through Vodou priests and priestesses. Individuals come to practitioners privately to resolve spiritual, emotional, psychological, and physical manifestations of distress. Indeed, in the Haitian healing tradition, fine distinctions between physical and spiritual distress are not normally drawn. Rather, Vodou healers determine the origins of illness in problematic human or spiritual relationships and address imbalances in relationships, whether among living persons, the living and the dead, or the living and the spirit world[13]. With their emphasis on

Naming the Haitian Spiritual Tradition

Over centuries of African slavery in the new world, the faiths and spiritual traditions of Africans and Christian practices of Europeans mixed to produce unique religions in Caribbean societies, parts of Latin America, and the US South. The fusion of African and European elements in Haiti is generally referred to as "service to the spirits" includes specific patterns of music and dance called "Vodou". In the US, scholars commonly use the term Vodou to refer to the entire repertoire of practices to serve Haitian spirits. They distinguish between this term and the popular usage of "voodoo", which in the US has come to be associated with usually fictional attempts to harness supernatural powers to do harm to others[5].

Religion in Haiti

The oft-repeated saying that Haiti is 90% Catholic and 100% Vodou[14] simplifies the diversity of religious traditions and practices in Haiti. In addition to the widespread influence of Catholic Church, Protestantism has a long history in Haiti. Protestant churches gained members throughout the 20th century, and today about 16% of the population belongs to a Protestant faith. As much as 50% of Haitians practice Vodou, most of whom also identify with the Catholic faith[15].

restoring balance, healers in the Haitian spiritual tradition may work in collaboration with biomedical practitioners, who focus on physical manifestations of distress.

Contemporary Vodou Practice

Just as traditional Haitian Vodou was shaped by colonial slave society, revolution, and an independent rural peasantry, contemporary practices are changing in response to new realities. Urban social and economic forces erode the traditional structures of patriarchy and women have more autonomy in their daily lives. Similarly, in more fluid urban settings, female Vodou practitioners can become as powerful as male, a prominence they would not typically achieve in rural areas[16]. In rural Haiti, where several generations of extended families live in the same settlement and ancestors seem readily accessible in local burial plots, familial spirits and ancestors have a central role in Vodou practice. But ancestral authority is diminished in far-flung emigrant communities. Instead, the *Gede* class of spirits, who rule over cemeteries have prominent roles in rites and healing in US Vodou practice[17]. Gede are guardians of the threshold between the dead and the living and more generally oversee transitions from one state to another. In the US Gede spirits represent the diverse ancestors of all who gather as a Vodou family, including those who are generations removed from Haiti or who are not themselves Haitian[18]. With one foot in the land of the dead and one among the living, Gede are apt advisors to immigrants determined to construct a place for themselves in a new society without losing their connection to their traditional home.

Like other cultural traditions, the practice of Vodou helps maintain connections among immigrants, and between them and the country they left behind. Vodou also provides a framework for understanding and responding to the many challenges of immigrant life, guiding followers as they struggle to shape their destiny in new settings.

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Let us highlight your case

Have you, or a colleague faced a TB case that was challenging due to your patient's cultural beliefs or practices being dissimilar from your own? Have you experienced success in a case because you changed your typical approach based on something you learned about the patient's culture? If so, we'd love to highlight your case in an upcoming issue. Don't worry about producing a polished piece – we do most of the work! Please contact Jennifer at campbejk@umdnj.edu if you have some ideas.

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