



TB & CULTURAL COMPETENCY

Notes from the Field

New Jersey Medical School Global Tuberculosis Institute

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A Family Affair

Introduction

This case comes from a state health department nurse who lived in the small town located on a large Great Plains Indian reservation where this case unfolded. It involved an extended family spanning 4 generations, all of whom lived in the same 3-bedroom house.

TB Across Generations

The first family member to be diagnosed with pulmonary TB disease was its oldest, a 78-year old man who was known to everyone in the town as Roy. He had been ill for several months with a persistent cough, and was treated for respiratory infection over that period of time. Roy had a number of health issues: he was a diabetic; he had a diagnosis of end-stage COPD, leaving him dependent on an oxygen machine; and he was largely confined to a wheelchair. He was also a long-time cigarette smoker, and a heavy drinker. Perhaps all of Roy's health issues made it difficult for the staff at his local clinic and Indian Health Service (IHS) health center to recognize the signs of TB even as they grew more pronounced over time. On the last of several visits to the health center's emergency department, the staff collected a sputum sample from him before they sent him to a more comprehensive facility. Roy traveled to a big city hospital some 200 miles away, where he was admitted. The



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results from his sputum came back to the IHS center as culture positive for TB, and they notified the big city hospital, where the diagnosis was finally made. He was then started on a standard 4-drug regimen for TB disease.

Roy had been infectious for about 10 months and had sought care on several occasions, so nearly 100 health care workers at 3 different organizations were identified as contacts and tested for TB infection. Luckily, none of them was found to be infected. Other than going for medical care he tended to spend most of his time at home, and that is where my contact investigation began. There were more than 20 people in the household, including 2 very young children. We also identified other family members who had visited Roy as possible contacts in the months before he was diagnosed. In total, we tested 38 family members and identi-

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fied 2 additional cases of pulmonary TB disease – a 17-year old granddaughter of the patient and her 2-year old son. Based on the granddaughter's sputum sample she was determined her to be non-infectious. In addition, since young children with TB disease are not considered infectious, there was no attempt to separate them from the rest of the family in the house. None of the other contacts that we tested were positive for TB infection, so no additional medical evaluation of contacts was necessary.

Since Roy remained at the city hospital for a while, the 17-year old, Christine, and her toddler son Jason, were really my first patients. They both started directly observed therapy (DOT) with me and that was when I really got to know Christine, though we had seen each other around town since she was small. Christine was 7 months pregnant at the time and had been going to high school part-time in order to be able to care for Jason. She was anxious not to fall further behind in school because of illness, so she was motivated to take her TB medications. As is true with many children, it was difficult for her to coax Jason when he resisted efforts to give him his medication. We struggled to find ways to make it easier for him. Finally, we had success giving him the crushed pills in chocolate pudding to hide the taste, and when he got tired of the chocolate flavor we alternated with other flavors. By working together to give him his doses, Christine and I established a good relationship, and I often remained at the house after their DOT to review her homework with her. Staying a while also gave me a chance to talk with her about what information she had shared with others in the community about their diagnoses of TB.

The News Travels

Given the crowded conditions of the household, isolating Roy from the rest of his family was not possible, so he stayed in the hospital for about 2 months until he was no longer infectious. Well before he returned home, word was already circulating in our small town about his diagnosis of tuberculosis disease. I had heard about it from various sources even before I was assigned to conduct the contact investigation. As a result, several town residents called the health department asking for a TB test even though they had not been identified as contacts. In addition, employees from the high school approached me to ask whether



Photo Courtesy of the Indian Health Service/U.S. Department of Health and Human Services.

Christine should be allowed to attend school, and the staff at the day care center that Jason attended expressed similar doubts. Therefore, I scheduled an educational session about TB transmission and its risk as well as infection control strategies for staff at both locations, but I got more than I bargained for when a few dozen parents showed up at my session with the day care workers! For a time it seemed like wherever I went I heard speculation about why TB had surfaced in this particular family. My first response was to tell people that I couldn't confirm or deny any information about a medical case. However, I took the opportunity to explain and reinforce basic information about disease transmission, progression, and treatment. I reviewed how the health department determines infectiousness and the questions used to identify contacts of an infectious case. People appeared to leave the session with the understanding that if I had not yet approached them about possible exposure to a TB case, it was because it was determined that they were not at risk. It turned out to be an education for the entire community, since many members had never thought much

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about TB in this day and age – for many people it was something from their grandparents' time that no one faced anymore.

I also had the opportunity to educate my colleagues at the local hospital when it came time for Christine deliver her second child. At the time she was admitted to the hospital she told the staff that she was being treated for TB and asked them to contact me so that I could make a regular DOT visit. The hospital staff immediately put her in an isolation room even before they contacted me to confirm her diagnosis and treatment. When I did talk to the staff, I explained that there was no need for isolation since she was not infectious. I also explained the process of DOT. As with the rest of the townspeople, they had little experience with TB.

Once Roy was discharged from the hospital he became part of my daily DOT visits. It was never any trouble to find him, since he was frail enough to be housebound, but I learned to get to the house early in the mornings with his medications. I needed to arrive there by 7:30 in the morning, because if I came later in the day, after he had already been drinking, it was more likely the medication would upset his stomach. He also did not appear to be regaining the weight he had lost before he was hospitalized, and the family reported that they couldn't get him to eat much, so I brought him a liquid nutritional supplement along with the medications.

The Roots of TB Disease

The source of Roy's disease was initially a mystery to me. He had been housebound for some time before feeling ill, and there were no documented cases of TB among the family's many visitors. After much probing, it eventually emerged that TB in this household had roots in the past. I had spent quite a bit of time talking with Roy and his wife before they remembered that an elderly relative had been very sick with TB in the 1970's, and had been treated by the Indian Health Service (IHS). I went to the regional IHS facility to look through the old disease registries to find the case. After going through several volumes of charts, I located the case that he told me about. I saw that Roy, his wife, and other family members had been identified as contacts and had been prescribed treatment for latent TB infection. I asked Roy if he remembered being prescribed any

medication when their relative was sick. He didn't remember it, but his wife did. She reminded him that she had completed treatment for LTBI, but that he hadn't. They joked about him being something of a wanderer in those days. I gathered that they were referring to him being away from the house for periods of days and even weeks, sometimes working and sometimes out with his friends.

My research into the case proved worthwhile, because many members of the family were anxious to discover the source of the disease that seemed to spring up among them without warning. Some blamed one member, others another. A brother visiting from California came under particular suspicion, since he had been staying at the house before Roy was hospitalized and the family claimed that brother had a chronic cough. Several family members were insistent that I test him. I shared with them that a TB infection can be latent for many years and can become active and progress to TB disease when a person is immunocompromised. I



pointed out that aging, diabetes, a damaged respiratory system, and heavy drinking had left Roy vulnerable to the infection that the body had contained for many years. I assured them that we were working to identify and test all people at risk of infection.

Photo Courtesy of the Indian Health Service/U.S. Department of Health and Human Services.

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Lasting Rewards

Dealing with 3 cases of TB in a single household was a challenge for the family, and sometimes for me, but treatment in all 3 cases was successfully completed. In addition, Christine and I developed a strong relationship that persisted even after she was cured. I was able

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DIABETES AND TB ELIMINATION IN NATIVE AMERICANS

Tuberculosis was once a leading cause of death among American Indians and Alaska Natives (AI/NA)¹. Even though TB was brought under control in these populations in the second half of the 20th century, diabetes has re-emerged as a serious community health threat in the past 2 decades.² AI/NA youth have experienced the most dramatic increase in diabetes, with a 68% jump in diabetes diagnoses from 1994 to 2004.³ Among the patient population served by the IHS, 16.5% of adults age 20 and older had diagnosed diabetes in 2007.⁴ This contrasts with national estimates of diagnosed diabetes in 6.6% of non-Hispanic, adult whites and 11.8% of adult African-Americans.⁵ These numbers don't include the additional 32% more people estimated to have undiagnosed diabetes in each demographic. The IHS further estimates that an estimated 30% of AI/NA are pre-diabetic.⁵ Finally, AI/NA suffer worse diabetes-related health outcomes than the general population, with a 30% higher risk of death due to diabetes⁴.

The IHS and U.S. Congress have responded with

increased funding and the establishment of the Special Diabetes Program for Indians. Today several hundred locally run programs in 35 states are funded through this program and provide diabetes treatment and prevention services that are congruent with the resources and cultural orientation of their communities. The Special Diabetes Program for Indians aims to provide comprehensive diabetes-related education, treatment, and support for management of co-morbidities among diabetic and pre-diabetic AI/NA.⁶ One potentially devastating co-morbidity of diabetes is increased susceptibility to TB infection and disease.⁷

At least as early as the 17th century, treatises on TB observed a connection between diabetes and the progression of TB disease.⁸ A review of recent studies confirms that people with diabetes are at an increased risk of TB infection and of progression from infection to TB disease, although the mechanisms that initiate this increased susceptibility are not entirely understood.⁷ Furthermore, studies cited in the review found that TB patients with diabetes were more likely to experience increased infectious-

“Great care must be taken to ensure that patient rights — especially the right to privacy — are protected to the fullest extent possible so the patient-health care worker relationship is not compromised; this relationship must be strong enough to last throughout the time it takes a TB patient to complete therapy.”

Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention Division of Tuberculosis Elimination, Self-Study Modules on Tuberculosis 7: Confidentiality in Tuberculosis Control, p 6.

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to help her access housing services and give her a recommendation for part-time work, both of which helped her establish her own household with her young sons. Overall, I think the experience was a positive one for the community as well. Through the well-attended educational sessions I provided, community members were able to learn, seeing the examples of Christine, Jason, and Roy, that TB can be cured with appropriate treatment and a good bit of determination.

LESSONS LEARNED:

Focus on Individual Patient Needs

Although a single house contained the three TB cases and several contacts described in this case, the people involved each had distinct needs and concerns that were met by the state nurse.

- Christine benefited from the attention she received

ness and severity of TB, increased treatment failure, and increased mortality.⁹

While management of co-occurring diabetes and TB presents challenges to healthcare providers¹⁰, the association of the two diseases also poses a potential threat to global efforts to control TB. As the global prevalence and incidence of diabetes rise, so too do the numbers of individuals particularly vulnerable to TB infection and disease. In some parts of this world, co-infection with diabetes may present as grave a threat to TB control as co-infection with HIV, yet the diabetes link is largely neglected in global and national strategies.¹¹

The Special Diabetes Program for Indians sites, with their emphasis on community engagement, preventive care, and support for wellness, may be an effective partner for TB programs wishing to increase awareness of and responses to TB risk among populations particularly vulnerable to the disease. Similarly, partnerships between diabetes programs and TB prevention efforts may be effective in other communities at heightened risk for both diseases, such as African-Americans.

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due to her own DOT visitations, but particularly from the extra help she needed to meet the challenge of getting her toddler to take his TB medications. Additionally, she benefited from the nurse's interest in helping with her schoolwork and support for her ambition to establish an independent home for herself and her sons.

- For Roy, who was unable to reduce his alcohol use while on treatment, it was important to adjust his DOT to early morning before he started drinking and the additional nutritional supplement helped his recovery.
- Family members were deeply concerned about how TB had come to affect their family. Their trust in the nurse overseeing their family cases was strengthened by her efforts to provide them with a full explanation of how Roy developed TB disease, especially since a senior member of the family corroborated the explanation.

Confidentiality is a Joint Effort

Safeguarding patient confidentiality in the course of contact investigations, education in congregate settings (like schools), and throughout the course of TB treatment is a challenging aspect of TB control. Patients and family members may be the first to disclose information about a diagnosis of TB to others within their social networks, as in the case presented in this issue.

However, such disclosure does not release healthcare workers from the obligation not to discuss patient information without the consent of the patient. This case highlights strategies to maintain patient confidentiality when some information about the case is widely known. This can be accomplished by:

- Asking the patient who she/he has told about the diagnosis and discuss how the healthcare provider plans to respond to any questions from people who ask about the case,

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- Exploring with the patient the possible ramifications of sharing health-related information with others at work, school, or other congregate settings.
- Redirecting questions from the public about an individual patient to provide education about TB transmission and control,
- Modeling respect for patient confidentiality when interacting with the public, even when the identity of a TB case is widely known.

Toward Culturally Responsive Healthcare: The Indian Health Service

The promise of healthcare played a role in the establishment of Native American communities within the larger U.S. society. In the 18th and 19th centuries, treaties between the U.S. government and native Tribes often included healthcare among the payments and services that the U.S. agreed to provide in exchange for enormous tracts of native-controlled land.¹ However, there was no overarching legal foundation for health services in native communities until the 1920's, and a corresponding institutional basis wasn't established until 3 decades later.

Founded in the 1950's as part of the Bureau of Indian Affairs, the Indian Health Service (IHS) was the force behind the first modern public health efforts on U.S. reservations, including sanitation systems, childhood immunization, and reducing the burden of tuberculosis disease. Today the IHS is an agency of the Department of Health and Human Services and provides health care services to 57% of the approximately 3.3 million U.S. American Indians and Alaska

Natives (AI/NA) living on or near reservations and in urban areas. The mission of the IHS is to provide comprehensive, culturally acceptable personal and public health services to AI/NA. Its facilities extend throughout the continental U.S. and Alaska, from urban areas to rural and remote settings where its health centers and village clinics are the primary or sole local health care provider.²

While the IHS can point to many remarkable achievements, including sharp reductions in the incidence and mortality of TB among AI/NA in the late 20th century, it also faces daunting challenges. It serves populations that are often geographically isolated, with less education and more unemployment than the U.S. population overall, 25% of whom live below the poverty line.³ Life expectancy for AI/NA is 2.4 years less than Americans of all races, and the rate of infant mortality is 40% higher than that with white Americans. AI/AN populations experience disproportionate mortality due to TB, alcohol use, cervical cancer, diabetes, motor vehicle accidents, and other forms of accidental injury, as compared to the rest of the U.S. population.⁴ After decades of improvements, health disparities between AI/NA and the U.S. population overall have begun to increase.⁵ The IHS acknowledges that many of its facilities do not have the capacity to meet the needs of its patient population. It is widely acknowledged that the agency is inadequately funded to provide comprehensive quality care to all AI/NA populations that rely on its services.⁶

In addition to direct service provision, the IHS works in collaboration with Tribes and Tribal health boards and is a vital partner in sanitation and environmental health projects in AI/NA communities. As illustrated in the case featured in this issue, the IHS also collaborates with state, county, and municipal departments of health.⁷ Partnerships with local providers and participation in projects to improve sanitation and living conditions may strengthen the IHS's capacity to respond to the social and cultural needs of the communities it serves. The IHS has supported innovative healthcare programs, such the integration of Navajo medicine men into hospital-based care teams⁸ and the use of midwife-based protocols to increase the number of women successfully delivering vaginal births after having delivered by caesarean section.⁹

The IHS has been a major source for training and education for AI/NA healthcare professionals and support staff. These human-resource capacity-building efforts have fed back into the IHS workforce: currently



Photo Courtesy of the Indian Health Service/U.S. Department of Health and Human Services.

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50% of full-time IHS providers are of AI/NA ethnicity, as are the overwhelming majority of full-time administrative and technical staff. The incorporation of increasing numbers of AI/NA healthcare providers is an important step towards culturally competent care in IHS facilities, as is the increasing devolution of administrative responsibilities from IHS officials to local health boards and Tribal governments.¹⁰

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Photo Courtesy of the Indian Health Service/U.S. Department of Health and Human Services.

American Indian and Alaskan Native (AI/AN) Population At a Glance

"The American Indian and Alaskan Native (AI/AN) population is comprised of 564 federally recognized tribes with heterogeneous geographic ranges, cultural backgrounds, and socio-economic characteristics. AI/AN communities also differ widely in health indicators. A 2003 review of health data from the 36 states served by the Indian Health Service found marked regional differences.

- While 11.7 % of AI adults in the northern plains reported receiving a diagnosis of diabetes, 5.8% of AN adults reported having diabetes, compared to 5.7% of the non-AI/NA population in the 36 states.
- 29% of AN were obese, compared to 21.6% of Pacific coast AI and 18.7% of the non AI/NA population.
- Binge drinking was reported by 20.6% of Pacific coast AI, compared to 13.4% of eastern AIs and 14.6% of the non-AI/NA population.
- Important differences also exist between genders: 30% of southwest AI men reported binge drinking, compared to 9.3% of AI women.¹
- Similarly, a recent study of utilization of prenatal care among AI/NA women found significant differences among urban and rural populations, with lower rates of prenatal care use in rural areas and on reservations.²

Among the many challenges that the Indian Health Service faces is providing accessible, culturally relevant care that responds to a wide variety of health conditions, regional settings, and cultural contexts.

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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 Diane at Lucasde@umdnj.edu if you have some ideas.



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225 Warren Street, Newark, NJ 07101-1709
(973) 972-3270
www.umdnj.edu/globaltb