TB & CULTURAL COMPETENCY

Notes from the Field

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Engaging the Patient

Introduction

This case study is from a Southwestern state that is home to many Indian reservations.

A Patient with a TB Past

When I met Ritchie, he was in a hospital bed, weak and suffering from pulmonary TB as well as from the effects of alcohol withdrawal. I was wearing a mask as I attempted to get the names of anyone he had been in close contact with over the past several months. The circumstances worked against us getting to know each other, but over several visits to his hospital room, I gradually learned about his life.

Ritchie was a 52-year-old Navajo man who had been homeless and dependent on alcohol for most of his adult life. I was assigned to his case in the hospital after he was found on the street several days earlier, unconscious and acutely intoxicated with alcohol. When able, he gave a history of cough and weight loss over the previous few months. On evaluation, he had a chest X-ray that revealed upper-lobe infiltrates and a large cavitary lesion. Multiple sputum samples were found to be positive. He was admitted to the Medical Intensive Care Unit for management of alcohol withdrawal, and was started on standard therapy for suspected tuberculosis disease with pneumonia. The hospital staff notified us at the TB Control Program. We obtained and reviewed his records and began to interview him.

His records showed he had a long history of TB disease. Fourteen years earlier, in a neighboring state, he was diagnosed with pulmonary tuberculosis and was started on a treatment regimen. He was lost to follow-up and hospitalized again several months after his initial diagnosis. Treatment was restarted, but he left the hospital only to return through the emergency room a few months later. Records revealed that he had drug resistant TB. Because he had not been adherent to treatment, the state asked for and obtained a court order for him to receive treatment under direct supervision by the department of health. He apparently completed treatment in yet another state. Two additional states had also previously evaluated him for TB disease. He had no form of health insurance or any public benefits.

Results of the latest rapid drug susceptibility test showed that Ritchie had multi-drug resistant tuberculosis, MDR-TB. Pending results of the conventional susceptibility test, Ritchie received treatment for MDR-TB.

Getting the Full Picture

As his TB program case manager, I made frequent trips to Ritchie's hospital room. Communication between us was difficult. I felt uncertain about how much

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he understood about his diagnosis and the implications of having MDR-TB, because he was slow to respond to requests to confirm or explain his understanding. He also seemed reluctant to communicate information about his family and friends, his current living situation, and his past. I thought that part of our communication difficulties were rooted in his distrust of authority figures and also from language limitations. Ritchie could speak English but his first language was Navajo and many English health-related terms were likely unfamiliar to him.

Over time, our communication improved as I learned what kinds of questions provoked a negative reaction from Ritchie and how to address certain topics with him. For instance, if I described specifically how his illness might worsen if he didn't take his medication, he would respond angrily, as if I was wishing illness upon him. I learned to refer to the illness more indirectly, and talked about how TB progressed in general, rather than personalize it as 'his' illness.

I also looked for ways to make my visits a little more enjoyable for Ritchie who was so isolated in his room. I thought he might be craving something familiar to him rather than hospital food. One day I asked him what type of snacks he liked. He told me his favorites, so I started bringing snacks, sometimes a soft drink, a candy bar, nuts or chips. Sometimes it was a homemade burrito. It was my way of trying to get him to see me as a friendly person who truly cared about him and his well-being.

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Gradually I learned more of his history. Like many on the Navajo reservation, Ritchie's family struggled to make a living. Possibly because his mother may have perceived Richie as being a little slow, he started school at age 10 where he was put into first grade. He dropped out by third grade. When he was 15 he struck out on his own, moving around the western states. He has been dependent on alcohol since that time. Although he never settled back on the reservation, he stayed in touch with his family there and in neighboring states; in fact,

Navajo medicine man creating a sand painting for a healing ceremony.

he had been on the reservation for six months before his most recent diagnosis.

Richie never shared information regarding how to reach his family as part of my contact investigation; however I was able to get some information from the Navajo Nation. When I contacted his sister in a neighboring state, she was grateful for the news of him. As a nurse, she took a very active interest in his progress. She let the rest of the family know where he was and called me regularly for updates on his condition. She called Ritchie too and he seemed responsive to her calls.

We learned that Richie had been in a serious car accident several years ago. Doctors thought the accident could have caused head trauma, and may have limited his ability to communicate. This, together with a diagnosis of alcohol dependency and depressive disorder, led the doctors to schedule a neuropsychiatric evaluation. The results of the evaluation suggested that Ritchie was not competent to manage many aspects of his life since he was mostly unresponsive during the evaluation.

When Richie learned of this diagnosis, he was upset. His understanding was that he had 'failed' the assessment. His sister emphasized that much of the neuropsychiatric vocabulary would have been unfamiliar to Ritchie and that his suspicion of the psychiatrist may explain why he was unwilling to respond to questions.

The hospital staff decided to repeat the assessment. Ritchie was initially resistant to undergo a second evaluation. We arranged for a Navajo interpreter to be

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ACTIVE LISTENING

Communication skills, including 'active listening' are essential elements of quality healthcare.[1] In active listening, the clinician demonstrates engagement and emotional presence by giving close attention to not only the content of the speaker's message but also the emotions and feelings underlying the message. Focused attention on clues to unexpressed beliefs and concerns as well as their direct messages can help patients overcome reluctance to articulate their perspective on symptoms or diagnoses, out of embarrassment or fear.[2] Active listening involves verbal and non-verbal signs that the clinician fully understands and accepts what is conveyed.[3]

The open, exploratory nature of active listening is distinct from the deductive aims that guide diagnostic listening.[4] As one practitioner and teacher of active listening observed, "physicians' intense clinical gaze directed at symptom description, time line, modifying factors, and associated symptoms so focuses clinical attention as to make it difficult to recognize clues"[5] to patients' experience of disease. Active listening facilitates the suspension of diagnostic listening in order to open the door to the patient perspective.

"I think we have to find ways of presenting information that is not upsetting to the patients. Like prefacing our statements with 'The information I want to give you is a very difficult subject. It's difficult for me to give you the information, and it may be difficult for you to hear it. But both of us agree that we need to discuss this. And I don't wish you misfortune or want anything bad to happen to you, but here's the situation . . .' And then go into your subject matter that has to do with giving information about a disease that's incurable, or working with a dying patient, or discussing advance directives, or anything. You just have to get them prepared."[1]

1 Carrese J, Rhodes L. Western bioethics on the Navajo Reservation. Benefit or harm? JAMA 1996;274(10):826-829.

Engaging in active listening before allowing diagnostic listening to direct the dialogue between provider and patient may be especially useful in cross-cultural healthcare encounters, since active listening can also yield important insight into how patients prefer to receive diagnoses, guidance, and suggestions for their care. Communication style preferences vary among cultures and how information and suggestions are presented can dramatically impact on patient satisfaction and health outcomes.[6]

"When I speak with Navajo people about conditions, illnesses, outcomes, I don't speak to them directly; I do it in the third person. For example, 'You know some people have this condition, and this may happen to them. If we do this test to check for meningitis, there's always the possibility of bleeding or infection. Some people may have had those things happen to them.' That's how I teach and talk to people: 'Some people have these troubles.' It's more acceptable; you're not seen as wishing things on them."[2]

2 Carrese J, Rhodes L. Bridging cultural differences in medical practice: the case of discussing negative information with Navajo patients. J Gen Int Med 2000;15:96.

Navajo Medical Providers on Communication Style

In the traditional Navajo worldview, ways of thinking and talking about events are understood to influence the course of events. To speak about bad things, such as disease or suffering, is seen as bring them about.[7] Even people somewhat distanced from traditional ways may feel anxiety about explicit discussion of negative information, as did Ritchie when he chided his case manager for speaking directly about his illness and possible negative consequences in the case presented here. Speaking in interviews, Navajo providers discussed how they avoid directly naming illness and poor outcomes when talking to their patients.[8]

Key Elements of Active Listening

Space for communication	Dedicate time to listening and create a space in which communication is as private and uninterrupted as possible.
Attentive body language	Your body can communicate engagement and interest, or the opposite. Be aware of your: • Posture, • Eye contact, • Gestures.
Suspension of judgment	Consciously withhold diagnosis or analysis of the speaker's condition to create space for full self-expression.
	Making a positive or negative evaluation of the speaker inhibits the listener from absorbing further input from the speaker.
Strategic verbal cues	Give enough verbal feedback to encourage the speaker's expression, but not in such a way that the listener guides the dialogue.
Mirroring	Provide feedback: • Periodically paraphrase what has been said. • Ask if your understanding is accurate. • Include underlying emotions as well as content in the summary.
Active listening is not:	…asking follow-up questions that respond to the listener's need for information thereby diverting the speaker. …quickly agreeing or offering reassurance before the speaker has finished talking. …diagnosing or offering solutions.

Notes

1 *Nancy Edward, Wendy Peterson, and Barbara L. Davies, "Evaluation of a multiple component intervention to support the implementation of a 'Therapeutic Relationships' best practice guideline on nurse's communication skills," Patient Education and Counseling 2006 63:3-11; Aaron W. Calhoun and Elizabeth A. Rider, "Engagement and listening skills: identifying learning needs," Medical Education 2008 42: 1111-1146; http://www.acgme.org/outcome/comp/GeneralCompetenciesStandards21307.pdf.*

2 *Forrest Lang, Michael R. Floyd, Kathleen L. Beine, "Clues to Patients' Explanations and Concerns About Their Illnesses. A Call for Active Listening," Archives of Family Medicine 2000;9:222-227.*

3 *Kathryn Robertson, "Active listening. More than just paying Attention," Australian Family Physician 2005; 34:12, 1053-1055.*

4 *Baron, RJ "An introduction to medical phenomenology: I can't hear you when I'm listening," Annals of Internal Medicine, 1985.*

5 *Lang, 223.*

6 *Carrese J, Rhodes L. Bridging cultural differences in medical practice: the case of discussing negative information with Navajo patients. J Gen Int Med 2000;15:96.*

7 *Carrese J, Rhodes L. Western bioethics on the Navajo Reservation. Benefit or harm? JAMA 1996;274(10):826-829.*

8 *Carrese J, Rhodes L. Bridging cultural differences in medical practice: the case of discussing negative information with Navajo patients. J Gen Int Med 2000;15:96.*

ALCOHOL AND NATIVE AMERICAN COMMUNITIES

In the case presented in this issue, Ritchie achieved sobriety during his prolonged hospitalization, leaving behind years of steady alcohol use. The TB program staff offered to refer him to supportive services to strengthen his recovery and Ritchie attended one meeting of Alcoholics Anonymous. He found the meeting unhelpful and refused to return. Afterwards, he maintained his sobriety independently.

Ritchie's reaction to AA was not unusual among Native Americans. Many fundamental elements of AA are foreign to native healing traditions, including the separation of the ailing (in this case alcoholics) from the rest of the community and the public 'confession' of personal shortcomings or transgressions. While some tribes have developed culturally-specific adaptations of AA, there is still a need for culturally-relevant approaches to recovery from alcohol dependence in Native American communities.[i]

[i] *Abbott P J. Traditional and Western Healing Practices for Alcoholism in American Indians and Alaska Natives', Subs Use Misuse. 1998;33(13):2605-2646.*

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present during this evaluation. However, Ritchie refused her services. Nonetheless, the results of the second evaluation determined Richie to be competent.

To make his long stay less isolating, I encouraged him to take advantage of the activities offered in the hospital, but he did not want other patients to see him with a mask on, preferring to stay in his room. He said he did not want other Navajos to know he was sick. I was able to procure a CD player and brought CDs from the local library for him to play.

A Long-term Relationship

Ritchie was no longer infectious after a month of treatment, but we considered him a high-risk case because of his history of poor adherence and a presumed diagnosis of MDR-TB. In addition, he was currently homeless and an alcoholic, two situations which may present challenges with adherence to treatment. Therefore, the TB program requested that he not be discharged from the hospital.

We also explored other options to see Ritchie through several more months of treatment for MDR-TB. Our state program had limited resources to retain high-risk patients, but we had worked together with the Indian Health Service (IHS) in the past. The IHS provides treatment for residents of reservations, and it could collaborate in providing TB treatment to an in-patient. I was taking steps to determine whether Ritchie's previous stay on the reservation would constitute residency.

We were surprised when the results of his conventional drug susceptibility test finally came in. While rapid susceptibility testing had indicated MDR-TB, the conventional test showed pan-sensitive TB. Further testing on the initial culture verified the conventional test result. Ritchie had TB but not MDR-TB, meaning he no longer needed to be confined to the hospital. It turned out to be a rare case of faulty internal controls of the initial rapid test.

We now had to shift our focus to preparing Ritchie for the remaining months of DOT as an outpatient. The TB program arranged to pay an area motel for a room for Ritchie where I could provide DOT, and he was discharged from the hospital. Meanwhile, I took steps to help him secure SSI benefits.

Building a New Life

As I made DOT visits to Ritchie in the motel room, I suggested different activities to occupy his time and establish new social relationships. He rejected initial offers to go to an alcohol treatment program. Eventually he attended one Alcoholics Anonymous meeting, but could not relate to the process and refused to speak when it was his turn. He told me he would not return because he no longer had any desire to drink.

Ritchie has maintained communication with his family since his discharge, and even took a brief trip to visit them on the reservation.

I still see Richie regularly. He is doing well. He has a prepaid cell phone, uses the local bus system, and frequents the library to check out books, talking books and music CD's. It is gratifying to know that I may have played a small role in helping him forge a new life for himself.

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Lessons Learned

Invest in Listening

Communicating with Ritchie was difficult when I first met him. Although I initially felt as if he was not fully absorbing many of the things that I said to him, he began to ask more questions once he had more trust in me. I always tried to explain things to him in a way I felt he could understand. To this day he will ask me questions and if he comes to the office, he'll ask our staff as well.

The Value of Family Ties

Although his family ties were irregular over the decades that Ritchie was moving from state to state, those connections provided an important link when he was in the hospital as well as now that he is stable.

Build Links to Cultural Resources

When I first met Ritchie, the city TB program did not include Navajo health care providers, nor did we have well-established relationships with Navajo-specific organizations. The nearest Navajo interpreter was 100 miles away. In retrospect, not being able to draw immediately on culturally appropriate services may have impeded our ability to provide optimal care. It took time for us to locate key resources, which may have been more effective had we been able to incorporate them earlier. Notably, we drew an interpreter into Ritchie's case relatively late. Our general understanding of how he experienced his illness and diagnoses may have been enhanced if he had the opportunity to communicate at least partially in Navajo.

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