TB & CULTURAL COMPETENCY

Notes from the Field

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Showing We Care

In this article, we will explore the many challenges faced by both the patient and the public health nurse as we examine the collaborative approach taken to ensure treatment completion.

MY EAR HURTS

Abena is a 31-year-old stay-at-home mom who lives with her husband and four children, ages 7, 5, 3, and 2 years. She emigrated to the United States (US) from Ethiopia in 2008. Once in the US, Abena sought care for long-lasting ear pain which began many years prior in Ethiopia. The discomfort from her ear pain was compounded by a constant whistling noise in the ears, dizziness, headache and nausea—making it difficult to care for her children and carry on a normal daily routine. Abena initially visited a community health center for these symptoms, but was referred to an ear, nose, and throat (ENT) physician who treated her with antibiotics. Over the next several years, she made repeat visits to the community health center and urgent care for recurring ear pain. In 2016, she again visited the ENT physician for ear pain, neuralgia, headaches, and lymphadenopathy, this time receiving multiple courses of antibiotics, but still with little relief. In early 2017, Abena presented to the local emergency department with complaints of ear pain, nausea, weight loss, and cough. A CT scan revealed a lung mass and she underwent a bronchoscopy. She was referred to the health department with a presumed diagnosis of pulmonary tuberculosis (TB) and started on standard 4-drug therapy for TB. Culture results of the bronchoscopy specimens eventually confirmed *Mycobacterium tuberculosis*.

JUMPING RIGHT IN

My first home visit with Abena was in February 2017. After receiving notification that Abena was diagnosed with presumed pulmonary TB, I called her to schedule an appointment in the clinic and set up a time for a home visit. During the call, I spoke with her husband, Tarik, and made a plan for my visit to occur the following day at about 7 AM. When I arrived at the home, I was greeted by the children at the door. I immediately noticed suitcases lined up in the hallway as well as in one of the bedrooms. When I commented on the suitcases, the youngest daughter mentioned that the family was planning a trip to Ethiopia.

Abena's oldest daughter told me her brother needed help with his sneakers and asked if I could help to get them ready for school. Abena emerged from the bathroom and without speaking, quickly joined me in helping to finish getting the kids ready for

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school. It seemed my "mom mode" kicked in. We worked together like a well-oiled machine.

Once the kids were on the school bus, we went back to the apartment where I was able to make a proper introduction. Using an interpreter through the language line, I began to clarify the reason for the home visit, my role with the health department, and provide education about tuberculosis. During our discussion, I explained that she and her family would likely not be able to travel out of the country until we confirmed her diagnosis. Abena had little reaction but seemed to understand. I learned that while her husband often worked long hours, she tried to keep things running smoothly at home. It was also clear from our discussion that although Abena was very sick, she was trying to downplay the severity of her illness. Since she had been experiencing ear-related symptoms for many years without relief despite multiple doctor visits and courses of treatment, she told me her husband said it was all in her head. At times, Abena herself thought that she was going crazy. I assured her this was not the case. She was indeed sick and in need of treatment.

That evening I received a call from Abena's husband, Tarik. He was extremely angry and exploded in a stream of hateful and hurtful statements directed at me for telling Abena that their family could not travel to Ethiopia. He informed me that the airline tickets were already paid in full and said I had no right to interfere. My immediate reaction was one of utter shock and hurt, so much so, that I could not speak. Once I was able to get my emotions under control, I said "Listen, I understand you are upset. I'm sure you can hear that I am upset. Let's schedule a time when you can come into the health department and we can explain our concerns and discuss some options." He agreed to come in the next day.

For the next two months, I visited the home every day to provide directly observed therapy (DOT) and to help Abena with the morning routine of getting the children off to school.

Prior to the meeting with Tarik, I conferred with our State TB Nurse Consultant to investigate potential reimbursement of the airline tickets. Although it was a long shot, I knew how important it was to have Tarik onboard with his wife's treatment and this seemed like the only way to move him forward. In some cases, we had been able to do this before, and I was hoping we could it again.

For my own comfort, I arranged to have a male colleague join me during the meeting with Tarik. We began by simply explaining our concern for his wife's health. We also shared previous experiences with being able to negotiate partial reimbursement of airline expenses in similar instances with other patients. Tarik vented his anger a bit and we heard him out. We validated his concern for the lost finances and tried to reassure him. By the end of our visit, his anger had dissipated somewhat. I think having my co-worker there helped in this regard. He did not leave happy, but he was informed, and trusted that we would do everything in our power to get his money back.

For the next two months, I visited the home every day to provide directly observed therapy (DOT) and to help Abena with the morning routine of getting her children off to school. During this time, we were able to have the children tested, all of whom were negative. Tarik refused to allow window prophylaxis despite my best efforts to convince him of its importance in young children. Ultimately, none of the children were diagnosed with latent TB infection.

With her limited English proficiency, Abena divulged

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Pictured above: Smiling young Ethiopiam mom.

T'ej Honey Wine

The Encyclopedia of World Environmental History states that T'ej is thought to be one of the oldest alcoholic beverages ever produced. Very simply stated, making the home-brewed honey wine involves a process of fermenting honey, water, yeast and gesho (woody buckthorn twigs). The honey used to make T'ej accounts for much of the honey produced and sold in Ethiopia. Described as both sweet and pungent, T'ej is made and enjoyed in private homes and T'ej 'bets' (houses) all over Ethiopia. It is traditionally served in a berele flask, (see photo). Depending on fermentation, T'ej can have an alcohol content of about 7-11% but can also be as high as 21%.

PHOTO: GUY SHACHAR

Pictured above: Group of men enjoying T'ej in a T'ej bet.

Some American wineries bottle it for commercial sale. Today you can find modern brands of T'ej in bars, grocery stores or wineries where it is produced.

to me physical discomfort that she was experiencing related to genitourinary symptoms and an embarrassing dark furry line running down the middle of her tongue. I surmised this was something she did not discuss with her husband and appreciated that she felt comfortable enough to share this information with me. Although I did not attribute these symptoms to TB or her treatment, I listened to her concerns and suggested she seek care from a gynecologist. However, the dark line on her tongue was quite puzzling.

During DOT visits, I would also occasionally help Abena with grocery shopping and tasks in the kitchen. Much of her work in the kitchen revolved around making what seemed to be a home brewed tea she enjoyed drinking with Tarik in the evenings. It was a very time consuming process of preparation and fermentation, so I would jump in to help with small tasks if my visit coincided with this activity.
At least once a week, I would make a second home visit in the evening so I could also meet with Tarik to keep him informed and invested in his wife's treatment. On my first evening visit, I was invited to join them on the floor for tea as we talked. I sensed this was important to Tarik so that became our routine during my evening visits. Tarik spoke perfect English but I used the language line to be sure Abena was getting accurate information and was fully aware of what Tarik and I discussed. Aside from her drug serum levels being somewhat low, treatment was going smoothly.

PLOT TWIST

About eight weeks into Abena's treatment, drug susceptibility test (DST) results revealed that she had multi-drug resistance (MDR) TB. I anticipated that any change in Abena's treatment plan might cause Tarik some concern and may require earning his trust again. Therefore, I arranged a time for an in-person meeting with Tarik at the health department and included a laboratory staff member. I explained the recent test results and the implications of drug resistance as it related to Abena's treatment. The lab technician was able to describe the step-by-step process of testing in the lab and how a

person is determined to have MDR TB. It was through this conversation between the three of us that Tarik gained confidence in our knowledge of TB. At this point, I felt very relieved that he now understood that his wife was sick with MDR TB.

However, when I began to discuss the need for a clinician with MDR TB expertise to be involved in designing Abena's regimen change, Tarik expressed that he was not comfortable with this. I was very direct and asked him: "What do you need? I want you to understand this and be part of your wife's treatment, so tell me what you need to be able to do that." Upon hearing that he needed to see the clinician for himself, I contacted the infectious disease physician who provides consultation on the management of our MDR TB patients to discuss the situation while explaining the family's needs. The physician readily agreed to accompany me to Abena's home for a meeting. Over the course of two and a half hours in the home, he conducted a complete physical exam and made sure he was familiar with Abena's history, symptoms, and other complaints (sans her genitourinary symptoms). He answered all of the family's questions, which went a long way toward retaining Tarik's trust. Her regimen was soon changed appropriately based on the DST results and treatment was extended to 14 months.

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MISSING SOMETHING

As per the health department protocol, drug serum levels were done routinely. Repeated test results showed that Abena's drug levels were low. Combined with the fact that she was also not finding any relief from her genitourinary issues, I found this very perplexing. I had a nagging feeling we were missing something and often discussed the situation with my colleagues to figure out the missing piece to this puzzle.

On one particular home visit, Abena asked if I would help her snap some twigs for her fermented tea. As we were doing this, I inquired how the twigs are used. She described the process of fermenting the honey with the twigs and other ingredients. There was a 5-gallon bucket with what appeared to be a T-shirt tied over the top. I had seen this bucket so many times before that it had just become part of the kitchen background.

When I asked her if she drinks the tea, she said "Oh yes, this is something my husband and I do in the evenings when he gets home. It ferments and so, it's kind of, well it's not like alcohol but it's similar." Throughout the course of our conversation, I realized that she was drinking a lot of this tea and I suddenly had a feeling that this was the missing piece! Something about this drink was affecting her treatment and possibly causing her much discomfort.

When I shared my thoughts with a colleague who was familiar with Abena's case, he offered to put me in touch with a nurse from Eritrea who might be able to shed some light on the brewed tea and its relation to cultural practices. To my surprise, I learned that this drink was not a tea at all! The nurse explained that the drink was T'ej, an ancient Ethiopian honey wine.

After some discussion with our consulting MDR TB clinician and our nurse case manager, we agreed there might be some correlation between the honey wine and Abena's inability to adequately absorb the anti-TB medications. I decided that it would be best to discuss these concerns with Abena and her husband. Once again, I was nervous because this was a nightly ritual shared between them and I believed Tarik expected his wife to participate.

I first explained my continued concern regarding her drug serum levels. Tarik was familiar with this concept from our discussion with the lab technician at the onset of her MDR treatment and he knew this to be an important component of treatment. I chose my words carefully, but I did come right out and say that I, along with the treating physician and nurse case manager, suspected that something about the honey wine was affecting her ability to fully absorb her TB medications. I acknowledged the drink was very important to them and I understood it to be part of their culture, something they enjoyed together as a husband and wife. I explained that I did not want to take that away from them and I was careful not to say Abena could not drink it. Instead, I suggested that if they were both willing, we could modify her intake. To my surprise, they both readily agreed to have Abena cut back on drinking T'ej.

TREATMENT COMPLETION

Abena was eventually able to cut down her intake of T'ej to about a quarter of what she was previously drinking. I found out later this was a big decrease. After a few weeks, her drug serum levels were within normal range, and she eventually completed treatment within the recommended time frame. Her genitourinary symptoms began to subside, for which she was most grateful. She was much more comfortable and her mood improved as well. Only after considering all other possibilities were we able to safely assume the missing piece was the T'ej honey wine. We never did figure out what it was about the T'ej that interfered with her drug absorption. Perhaps it was the alcohol content or something about the buckthorn root or something else so specific to Abena and this particular honey wine or the method of home fermentation. Post treatment, Abena is doing well. The ear pain she suffered with for years and the mysterious line on her tongue have significantly diminished. She is mentally and physically more available for her family, to the delight of her children. She again enjoys sharing T'ej with her husband, although in much smaller quantities.

CONCLUSIONS AND REFLECTIONS

In direct TB care, we should aim to work within the limits of our competencies and collaborate with our colleagues to gain insight for addressing specific issues or challenges. Directly or indirectly, I utilized nearly **every** member of our team for this case. Invaluable to keeping this family engaged in treatment was our ability to mobilize resources for rent assistance when we were unable to secure a refund for the airline tickets. Giving that piece over to the nurse case manager allowed me time to arrange for other aspects of Abena's care. Consulting with and requesting assistance from lab personnel and our consulting TB physician was a huge factor in having a successful outcome. Conferring with my colleagues led to some helpful suggestions as well. One that stands out was a suggestion to replace some of Abena's honey wine with sparkling cider. Abena was concerned about Tarik's reaction to her really cutting down on partaking in their nightly ritual. She loved the idea of having an "out" if she needed one. It helped her feel more comfortable about cutting back on the honey wine. In hindsight, I have wondered if perhaps some of her symptoms of dizziness and nausea could have been signs of alcohol intake rather than symptoms of illness.

As I look back on this case, I am reminded about the extent to which we are willing to go in order to help our patients. Working with patients in their homes sometimes requires this kind of willingness.

We can never know what small thing we might be able to do to help someone. We can, however, usually foresee when this type of help will have a trickle down effect, often moving someone a step closer to treatment completion. I believe that is where the willingness comes from. Helping Abena get her children off to school most days was an immense support to her. This small task alleviated her feelings of being overwhelmed and exhausted and helped her to feel that treating her illness was doable. This experience also made me realize how far building rapport and trust can take us as we negotiate treatment.

Working in healthcare, particularly in TB care, brings us up-close and personal with our patients. I consider the unique opportunity my job affords me to get to know people I may not have otherwise met, a privilege. My faith plays a large role in my approach with patients. Long before I know who my patients are I pray for them, and pray that I will treat them with dignity, and honor God by showing them the respect and reverence they deserve. Building trust and developing a strong rapport with the patient and family can be the key to successful outcomes. But building rapport and trust is no easy task and sometimes may seem to require as many different approaches as there are people. That said, becoming increasingly proficient at clear, goal oriented, empathic patient communication may serve us well as we navigate communicating across many cultures.

The table below highlights some of the foundational skills and principles important for building rapport as we communicate with patients and their families.

Adapted from Epner & Baile. (2012). Patient-centered care: the key to cultural competence. Annals of Oncology, 23(Suppl 3): 33-42.

PRINCIPLES AND SKILLS FOR IMPROVING PATIENT COMMUNICATION

Principle 1: Everyone has a profound need to be heard and to be understood

This is where therapeutic patient rapport starts. Inviting the patient to tell the story of his or her illness (the patient narrative) is in itself therapeutic. Taking a personal history is an opportunity to demonstrate you are interested in the person, not just the patient. Exploring the patient's concerns gets us on the same page as the patient, which can assist in treatment negotiation.

Relevant Skills, Phrases, Examples, and Ways to Explore:

- Listen attentively when the patient talks
- Allow space (silence) in the conversation
- Use open-ended questions; these usually begin with why, how, or tell me about
- 'What kind of help will you need from your family during treatment?'
- 'Tell me about how you take your current medications'
- 'Tell me more'
- 'Please tell me what you understand about TB'
- 'What do you most fear about TB?'[1]
- 'What concerns do you have about TB treatment'[1]
- 'What would you like to discuss today?'
- 'Tell me about your family'
- 'What do your children understand about your illness?'

Principle 2: All people really care about is being cared about

Create the right atmosphere: be friendly, greet everyone in the room, sit at eye level. Telling the patient that you will do everything you can to see that his/her TB is cured, and then doing so, builds trust and rapport. Responding to emotion with empathy allows a patient to feel that you are tuned into him/her. Be clear, avoid jargon and keep explanations at a level the patient can understand. If the patient uses the term 'bad stomach', resist the urge to replace the phrase with a medical term. People need the truth, delivered sensitively. Balance optimism with credibility - 'TB can be cured'.

Relevant Skills, Phrases, Examples, and Ways to Explore:

- Respond to emotion with empathy
- 'I wish [things] were different'
- '[This] must be very difficult for you'
- 'I can see you were hoping for better news'
- 'I wish we had [better, shorter] treatments for you'

[1]Kleineman & Benson. (2006). Anthropology in the clinic: the problem of cultural competency and how to fix it. PLoS Med 3(10): e294. https://doi.org/10.1371/journal.pmed.0030294

PRINCIPLES AND SKILLS FOR IMPROVING PATIENT COMMUNICATION

Principle 3: Family is an extension of the patient

Almost all people have a profound love for and loyalty to family, especially immediate family. Asking a patient about his/her family (see Principle 1) opens an emotional window. Commenting on positive familial relationships demonstrates you care enough to notice family dynamics which may play a role in the patient's treatment experience.

Relevant Skills, Phrases, Examples, and Ways to Explore:

- Acknowledge the work and support of the family
- 'I can see the love between you and your family'
- 'You have done a great job supporting your [husband/wife] through his/her treatment'

Principle 4: Physical touch is a powerful force that can be destructive or healing

As a very general rule, if you are a man, do not extend your hand to a woman unless she extends hers first. If you do not know how to greet someone, simply smile and nod respectfully.

Principle 5: Non-verbal cues are powerful

People transmit as much or more information by non-verbal cues as they do by words. Be perceptive and adaptive. Strong emotions, such as fear, sadness, pain, and anxiety are usually obvious. Other emotions may require more focused attention to be perceived. Establish eye contact with the patient that is commensurate with their eye contact with you. If they avert your gaze, establish less eye contact.

Principle 6: Spirituality is important to nearly everyone

One's faith in a higher power often becomes increasingly important during times of duress and vulnerability. Validating someone's faith shows respect and support.

Relevant Skills, Phrases, Examples, and Ways to Explore:

- 'What role does spirituality play in your life?'
- 'How has faith helped you during challenging times?'
- 'Has your [clergy] been involved in your spiritual care during your illness?'
- 'I respect your faith. Faith is powerful medicine'

Principle 7: Allow the patient and family as much control as possible

Negotiate the content and flow of the conversation to give the patient control over the meeting. Respect patient's needs and priorities as long as they are reasonable, and sometimes even if they are unreasonable. When the patient needs guidance, confidently help him/her make well-informed decisions.

Resources and References

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