



TB & CULTURAL COMPETENCY

Notes from the Field

GLOBAL TUBERCULOSIS INSTITUTE

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Patient-Centered TB Care: Meeting in the Middle—Nigeria to New Hampshire

This issue highlights Tanwa, a young woman from Nigeria, during her diagnosis and treatment for multidrug-resistant (MDR) tuberculosis (TB) and the collaborative approach utilized by Dr. Elizabeth Talbot and the healthcare team to effectively manage her care. The newsletter includes both the perspectives of Tanwa and Dr. Talbot and explores cultural differences around the patient-provider relationship. We also include a brief point of view from a TB advocate and opportunities for patients to harness the power of their experience.

Tanwa's Story

I came to the United States (US) from a middle class family in the city of Lagos Nigeria in 2013. I had been vaccinated against TB a few months prior to traveling to the US because it was a mandatory requirement for obtaining a visa. When I arrived in the US, I had a TB skin test and a chest X-ray. I was informed that the skin test came out positive and I had a negative chest X-ray. I was prescribed treatment for TB infection and received Rifampin for 6 to 7 months, at what I later found out was an unusually low dose.

By late January 2015, I still was not feeling well and had also developed a cough and chest pain. The doctor ordered a test



Tanwa

for influenza and a chest X-ray. The flu test came back negative, while the chest X-ray was positive. The doctor said I had either very bad pneumonia or tuberculosis, and ordered that I check into the hospital immediately. I was very upset because it took them so long to diagnose what was actually wrong with me. I consoled myself that it would be pneumonia and not tuberculosis because I was very much aware of the stigma attached to tuberculosis. I was in denial.

I went to the hospital where I was admitted and immediately placed in isolation in a negative pressure room. My

Continued on page 2

Continued from page 1

symptoms had worsened and I now had a fever, vomiting, nausea and cough. It took a few days for me to be diagnosed with tuberculosis.

I knew about tuberculosis because it is a very stigmatized disease in Nigeria. One belief about this disease is that you cannot even share a plate or spoon with someone who has TB for fear that you might contract TB. I had friends who had TB in Nigeria, and one of my friends died from it because medications to treat TB are not readily available. The government offered free medicines through the health department, but they were not available to my friend. She went to a private hospital, but the medications given to her were not the right kind. We do not have protective masks in Nigeria or special areas in the hospital for isolation of people who are sick with TB.

Even though the medical staff in the hospital had informed me that I had tuberculosis, I was in denial and unable to deal with the diagnosis emotionally. At the time, I was working as a licensed nursing aide at a long-term care facility, and was worried about my job.

Since there is a stigma attached to tuberculosis, I did not even want to tell anyone in the Nigerian community where I live. No one outside of myself and my family knew that I had TB.

After 10 days, I was finally discharged from the hospital. Soon after I came home, I had multiple sputum tests and the first two samples came back negative. I did not receive the test result for the third sample. I did not know what was happening, but I had a bad feeling. I did not hear anything for several

days which made my anxiety and fear worse. Finally, on the fifth day, the health department called and instructed me to go back to the hospital right away. I was scared and did not know what to expect.

At the hospital, I was informed that I had a unique type of tuberculosis. When I heard this news, I thought, “Oh my God!” I was diagnosed with drug resistant TB, which required aggressive medications for treatment. A peripherally inserted central catheter (PICC) line placed for medicines that I needed to take intravenously (IV). I stayed in the hospital for a week and tried many different medications and was closely monitored. I was then sent home and placed on home isolation.



Tanwa getting released from hospital.

Challenges During Treatment

Deborah, my nurse from the health department, helped prepare me for what to expect with my illness and the treatment. I did my own research online so I was aware that there were some types of TB that could not be treated. I asked my doctor to be sincere with me, and tell me if she thought my TB could be treated, and she said yes. She prepared me for what to expect while I was on home isolation as well.

I had a hard time being on home isolation. It ended up being a total of four months, and I could not work during the whole time. During this time, the health department asked me a lot of questions about the people with whom I had spent time. All of my coworkers were tested for TB and I was concerned about whether the health department would tell my coworkers that I was the person with tuberculosis and the reason they were being tested. I did not want my coworkers to think badly of me, or to think that I did not take care of myself. The nurses reassured me that they would protect my confidentiality. While I was out, my coworkers kept in touch with me, my supervisor had also visited me when I was in the hospital. When I finally returned to work, I initially hid the reason for my extended absence from my coworkers and waited for some time to tell them that I had tuberculosis. They

had a mixed reaction—some were supportive, but others did not react kindly.

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I experienced problems with my health insurance as well. My TB case manager, Deborah, paid for some of my medications out of her pocket. When I met Dr. Talbot the first time, she asked me what she could do for me. I asked her to take me off home isolation, and she did. She is a great doctor; she is always asking questions to get to know me as a person and check on how I am doing. She expressed such care and concern for me. She was also able to help me with my insurance, so now I just pay my deductible and my medications are covered. The nurses assigned to me were also great; they always listen to me.

Nigeria and the United States

I am very grateful this happened in the US—I'm so lucky to be here. There are many differences in the care given here compared to Nigeria. In Nigeria, we do not have all the modern medical technology and do not have access to many of the medications. The technology is not available to detect drug resistance, or to have a PICC line placed so that I can receive the IV medications. In Nigeria, I would also have to pay the cost upfront before getting started on treatment. In the US, I get an incentive for taking my medications, and this would not happen in Nigeria.

Another difference is the doctors in Nigeria tell you what to do. Patients are not given any options, and instead, they are told what to do. As the patient, you do what the doctor says. Dr. Talbot provided me with a lot of options, which was overwhelming and different than what I had been accustomed to previously. My preference was for her to tell me what I needed to do to get through this experience and be well again.

My view about Dr. Talbot is that she is a specialist, who is very dedicated and passionate about what she is doing. She enlightened me more about my infectious disease and the medications that can be used to treat the disease. She also explained the side effects of the medications to me. I felt so important for the very first time because she was involving me in my care, the decision-making process concerning my health and the plan of action to beat this disease. I also felt relieved because my case [MDR-TB] is treatable and my fear has always been that it is not treatable.

A Long Journey

I have been through a lot this year. I had to drop out of school, because it was too difficult to take my medications, keep my medical appointments and go to school. I had a PICC line for 6 months and it was finally removed in August 2015. I had been shown how to give myself the IV medications at home. I also went to the hospital every Monday to get the dressing changed and for blood tests. After my appointments, I would go to work in the afternoon. Once the PICC line was removed, I felt like I had more control over my medications. Even though it is easier now, it will be a total of 2 years of taking many medicines before I am done with my TB treatment.

I have been so grateful for the support of my family and boyfriend while I was sick and during the treatment process. My boyfriend drives me to my appointments that are 3 hours away; he is very good to me. I plan to resume my studies to become a nurse. My experience has



Tanwa and her mother.



Tanwa and Dr. Elizabeth Talbot

reshaped my interest in nursing. Before I was diagnosed with TB, I was interested in becoming a labor and delivery nurse. Now having gone through this experience, I want to pursue infectious disease nursing and advocate for tuberculosis, both in the US and internationally.

Dr. Elizabeth Talbot's Story

I have been grateful to be part of the care team for Tanwa, who is an intelligent, kind young woman who immigrated to New Hampshire in September 2013 from Nigeria. When she arrived to the US, she tested positive for tuberculosis infection and, after a negative chest X-ray, was prescribed a low dose of Rifampin for 6-7 months. We always wondered why she was given the wrong dose and duration of Rifampin for the treatment of TB infection, and whether that had any role in the development of MDR-TB, but cannot know.

She was doing well until January 2015 when, working

as a licensed nursing aide (LNA) at a long-term care facility, she sought urgent medical care after a sudden onset of cough and chest pain. Her chest X-ray showed a dense right-sided consolidation. Her symptoms evolved to include fever, nausea, and vomiting, and she was admitted to the hospital directly to airborne infection isolation. She was empirically started on Isoniazid, Rifampin, Pyrazinamide and Ethambutol but was also given Levofloxacin because the clinicians were worried about her prior history of treatment for TB infection. She was discharged on home isolation with daily Directly Observed Therapy (DOT) to monitor her medications while awaiting more information from the lab.

I was especially worried that Tanwa's TB might be drug resistant because Nigeria is a hot spot for MDR-TB. So we navigated a specimen from her bronchoalveolar lavage (BAL) for testing with GeneXpert. That specimen not only confirmed *Mycobacterium tuberculosis* but also showed Rifampin resistance. The specimen was then sent to the Centers for Disease Control and Prevention (CDC) for Molecular Detection of Drug resistance (MDDR) testing which showed that Tanwa's TB was indeed Rifampin resistant but also resistant to Isoniazid (INH), meaning she has multi-drug resistant TB. We stopped the INH and Rifampin and she was started on Amikacin and Linezolid, in addition to the Pyrazinamide, Ethambutol and Levofloxacin she was already on.

During each of our monitoring visits, the drugs and their possible side effects were discussed. Unfortunately (but commonly in the treatment of MDR-TB), side effects have driven multiple changes to her regimen. A patient-centered approach was needed to individualize her TB care in order to respond to her concerns and implement interventions to alleviate the side effects of TB treatment while maintaining a safe and effective MDR-TB regimen. In spite of the difficulties with the medications, she improved. Her cough resolved, she regained weight and her sputum cleared. She has at least another year of treatment, for a total of 24 months.

As a result of the drug resistance and her job in the in long-term facility, her home isolation had to be extended. She had a difficult time with isolation, both financially and emotionally. After four months, the clinical decision to discontinue isolation was based on her response to therapy, including smear and culture results. Tanwa was so relieved to be released from isolation but she continues to deal with the social consequences. She is still catching up on bills and insurance issues. Even with health insurance,

she is having financial challenges. We have been able to provide some assistance to help her understand and navigate her health insurance.

The United States and Nigeria

Healthcare workers in the US are trained to explain the risks and benefits of any treatment so that patients can make an informed decision about their care and be a part of the healthcare team as part of the patient-centered approach to TB care. During an early visit with Tanwa and her boyfriend, we explained the treatment options and I noticed them look at each other and smile. Tanwa explained she just wanted her doctor to tell her what to do, because that is typically what happens in Nigeria. I realized that we needed to be flexible, and respect her choices regarding decision-making. At the same time, I

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Treatment and Care

Culturally Sensitive Informed Consent: Insight from a Medical Ethicist

by Tim Lahey, MD, MMSc.

The provision of high quality clinical care includes the demonstration of respect for patient autonomy. One way we respect patient autonomy is to engage in shared decision-making with patients. This often involves describing the pros and cons of various treatment options and deciding which option aligns best with patient preferences.

Some patients may prefer not to hear the pros and cons. They may prefer to put their trust in the clinician's hands, perhaps experiencing anxiety at what they perceive are a dizzying array of options. Still others may prefer to engage with a clinician who is more directive, and may not appreciate having to choose between options. Such preferences may be culturally-determined, as described in this case, but may also be driven by individual patients' personal preferences.

Respecting these patient preferences for the style of care, whether culturally or personally determined, is a form of respect for patient autonomy and does not conflict with clinician ethics. In fact, flexibly aligning communication style to patient preferences is the highest form of respect for patient autonomy. Put another way, we should not be excessively paternalistic in our insistence that the patient engage with a discussion of the pros and cons of treatment modalities.

Operationally, clinicians can gauge patient responses to the initial provision of pros and cons around clinical care options and then shape subsequent communications with the patient accordingly, titrating the level of information given and decisional-support to patient preferences. In very rare instances, clinicians may confront a decision in clinical care that requires the patient to articulate a preference, and yet the patient refuses. This can occur when there is equipoise about which way to proceed is best, for instance regarding the provision of aggressive or symptom-directed end-of-life care. In such rare instances, the clinician should attempt to distinguish between patient abdication of their own decision-making role perhaps via a lack of decision-making capacity, or rather if the patient's refusal reflects a coherent articulation of a preference of clinical style that can be honored logically. In such cases, it can be helpful to engage a supportive consultation service such as an ethics consultation, palliative care or a shared decision-making service.

Tim Lahey, MD, MMSc, is a clinical ethicist, infectious diseases physician, Associate Professor at Dartmouth Geisel School of Medicine and Director of Education at The Dartmouth Institute for Health Policy and Clinical Practice.

Reference

Bernat, J. Ethical issues in Neurology, 3rd edition, 2008 Pages 30-31.

Tanwa has been an ideal patient. She understands the situation, takes things very seriously and has been instrumental in getting some of her contacts tested. She has been very cooperative with the daily DOT and always expressed willingness to do whatever it takes to get better. She has an excellent understanding of her treatment and is very on top of the things she needs to do for her own care. Tanwa has responded well to therapy and is expected to complete treatment. She has taken control of her health and what aspects of her treatment that she could. For example, she self-administered her IV Amikacin, which has empowered her. It has been rewarding to watch Tanwa grow from this experience, and I look forward to helping her make the transition to TB survivor and advocate.

Resources for Persons Affected by TB

Stories have immense power; their words teach, inspire



On the road to recovery

and heal. Stories help to validate experiences, challenge stigma and provide social support. There is a lot of stigma attached to tuberculosis, and many are afraid to speak about it or tell others that they have it. However, those affected by TB are speaking out—finding their voices and sharing their stories. The following links include places to hear stories and maybe share your own:

Reference:

Chen, Pauline, W. “When Patients Share Their Stories, Health May Improve.” *The New York Times*. 10 February 2011. Web 4 December 2015. Available online at http://www.nytimes.com/2011/02/10/health/views/10chen.html?_r=0.

TB Stories

Stop TB USA Stories

http://stoptbusa.org/?page_id=571

CDC Stories

<http://www.cdc.gov/tb/topic/basics/personalstories.htm>

MSF TB and TB Blog

<http://www.msfastcess.org/our-work/tuberculosis>

TB Alert Stories

<http://www.tbalert.org/what-we-do/tb-stories/>

The Truth about TB Stories

<http://www.thetruthabouttb.org/stories/>

TB Voices

<http://www.tbvoicesproject.com/>

Cultural Competency Newsletter Issue #14
“Finding My Voice”

<http://globaltb.njms.rutgers.edu/products/culturalcompetency/TB%20&%20Cultural%20Competency-Spring2012.html>

Cultural Competency Newsletter Issue #15 “From Isolation to Vocation”

<http://globaltb.njms.rutgers.edu/products/culturalcompetency/TB%20&%20Cultural%20Competency-Summer2012.html>

General Stories

Human Spirit Project

<http://humanspirit.epidemiotoemotion.org/stories/>

USAID Storytelling

<https://stories.usaid.gov/#intro>

When patients are empowered, they become essential participants in supporting TB prevention and elimination strategies. This may involve providing social support for others affected by TB and engaging in advocacy efforts to raise awareness and influence policies. Advocates for tuberculosis play an important role in increasing political will and investment in research, improving access to drugs and rapid diagnostic methods, and forging partnerships between communities and public health professionals. Here, one TB advocate, Carrie Fritschy, briefly shares how her experience with TB shaped her involvement in advocacy work and describes an opportunity for others who have been affected by TB and are interested in becoming an advocate.



Opportunities for Advocacy

by Carrie Fritschy

After many months of illness, my daughter, Scarlett, was diagnosed with TB in April 2013 when she was just 22 months old. During the experience, I wished I had someone to talk to who would understand my concerns. It was a hard time; it was scary and lonely. We didn't share this with anyone as we were encouraged not to and were scared of the reactions we would get. Even from our loved ones that we did tell, we got mixed reactions. People stayed away at first. People accused us of not vaccinating. It was a time where the unknown bred fear and I knew I wanted to fight that stigma and bring awareness and education, so that those who battle this in the future can have a better support system.

In June 2015, I attended a TB Survivor Communication Skills Workshop and saw survivors transform into public speakers and share their stories. At the training, we were provided an overview of what types of questions we may be asked in interview situations and then allowed the opportunity to share our stories in a one-on-one capacity with a reporter. Part of the training was the videotaping of our stories so that we could see how we presented ourselves and be provided constructive feedback on how to best convey our messages.

That piece was instrumental in giving us confidence and the knowledge that we can make a difference with our experiences. But truly the best gift it gave us was each other. The inaugural group of survivors now has a private Facebook group where we keep in touch and share our continuous journeys through TB and the work we are doing to raise awareness. It is an amazing feeling, being able to connect with others who have shared this experience.

NTCA | TB Ambassador's Project

The National Tuberculosis Controllers Association seeks to build a network of survivors to become Ambassadors. The TB Ambassador's Project, which aims to create a team of survivors to serve as TB Ambassadors willing to raise awareness. Our mission is to:

Create a team of survivors who will serve as TB Ambassadors willing to raise awareness about Tuberculosis with three fundamental goals:

1. Provide an informative and supportive community for patients and survivors.
2. Share personal stories to drive change at a local, state and/or national level.
3. Provide the media a TB patient perspective to educate and reduce the stigma of TB.

We are looking for more patients and survivors to join us on this mission. We will be holding a survivor training workshop in February 2016 in Denver, CO. If anyone is interested in applying for this training, you can contact me at carrie.fritschy@deluxe.com.

We would love to grow this project and create a support network for the TB community.

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!

If you have some ideas, please contact Jennifer at jennifer.k.campbell@rutgers.edu.



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