TB & CULTURAL COMPETENCY

Notes from the Field

GLOBAL TUBERCULOSIS INSTITUTE Issue #21, Fall 2017

In a New Country, She Had a Village

This case is brought to us by a Public Health Nurse in Minnesota (MN). The article describes her experience working with a Somali family after their arrival in the US from a refugee camp and subsequent move to MN. The case also highlights some of the challenges and successful strategies for treating pediatric contacts for TB infection.

BACKGROUND

I first met Rahma, a 32 year-old Somali woman and her family members while she was hospitalized for TB. Shortly after her arrival in MN, she began experiencing persistent cough, unexplained weight loss, and intermittent fevers. Without a primary care physician, Rahma sought medical attention at Urgent Care, where she was initially diagnosed with pneumonia and treated with antibiotics. This seemed to help for a while, but she decided to visit the Emergency Department when her symptoms eventually returned. By this time, Rahma was quite ill. Based on her symptoms and chest X-ray, she was quickly admitted to the hospital in airborne infection isolation (AII) for suspected TB disease, after consultation from the Infectious Disease physician. An IGRA test and sputum specimens were ordered, along with a chest CT scan which revealed left upper lobe tree in bud formations and cavitation. Based on the genotype results and symptom onset, we believed that TB was acquired after arrival to the US.

HOSPITALIZATION

Rahma was hospitalized for three weeks. This was partially due to the severity of her illness and concerns for her ability to tolerate the TB treatment. Extended family members visited daily, bringing Rahma home-cooked food. This proved to be very helpful, as she had lost a significant amount of weight.

Having home-cooked, culturally preferred food was vitally important to her recovery for both weight gain and gastrointestinal tolerance of the TB treatment.

There were several social concerns around her discharge. She was a single mother, too ill to care for her five children alone. All of her children needed thorough medical evaluation and possibly treatment with window prophylaxis. Rahma's initial misdiagnosis meant that she remained infectious in the community for a long period of time. Relying on a large, well established, extended family network for support resulted in extensive numbers of TB exposures, totaling 47 individuals. Of those exposures, 27 were children.

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A MOTHER'S CONCERN

During our first meeting in the hospital, Rahma expressed great concern about her children's health. She willingly provided written consent for us to discuss her illness with her family members, sharing their names and contact information. She was very accepting of her TB diagnosis, and in a resigned kind of way, willing to do whatever it took to protect her children.

Photo: Flickr

Mom with young child.

With assistance from a language line interpreter, we learned more about Rahma's background. Rahma explained that she, with her husband and five children, arrived to the US fifteen months prior, to settle with her husband's family. Six months later, she and her children moved to MN while her husband remained with his family in another state. The motivation for moving was not explained to me, but it was clear that she had financial difficulty and indicated that she was not receiving any financial support from her husband after the move. Looking back now, I realize Rahma may have been showing signs of stress and depression. After all, she was a single mother who was very ill, trying to establish a life in a new country. This, without any financial help from her husband, with whom it seemed she was recently estranged. Despite this, Rahma was very cooperative and eager to complete her hospital stay so she could return to her children.

She explained that upon arrival to MN, she and her children lived with her sister's family for many months until receiving financial benefits to rent their own apartment. She was attending English as a Second Language classes and receiving assistance for health insurance, food, and rent. Her sister was caring for her children while she was hospitalized, so my next visit was to notify and evaluate the sister and her family, which included two adults and three children. All were US-born, and considered high-risk contacts due to their young age. It was during this visit that I learned the scope of the contact investigation and potential TB exposure to a large number of individuals. In addition to the sister's family, Rahma and her children also spent a significant amount of time in the two adjacent apartments, where more extended family members lived. I was also informed that weekly religious gatherings were held at the apartment complex, which all of the identified families attended, plus two additional families. In total, ten of the twenty-seven identified children were deemed to be high-risk contacts. Since this would be a fairly large contact investigation, I knew we needed a plan.

EVALUATION

Extended family members were very proactive in getting medical attention. The matriarch and patriarch of the family had some knowledge of TB. They were both TST positive in the 1990's in Somalia but never took treatment for TB infection. Both were very willing to now be treated because of other diagnoses putting them at high risk for developing disease. Despite the lack of an established primary physician, medical appointments were scheduled and completed for all five of Rahma's children the next day with transportation assistance from the sister's family. One child was diagnosed with TB disease and another was

hospitalized for further evaluation, which resulted in a diagnosis of TB infection. Skin testing was performed for all members of the sister's family, and medical appointments were scheduled for those high-risk children. From the 47 individuals exposed, there was one secondary case of TB disease, seven persons with TB infection, and three whom refused evaluation and/or treatment for TB infection. All of the patient's sputum cultures were pansensitive, which meant that treatment of the contacts would be nine months of INH, without concerns for drug resistance.

As all of these contacts were being evaluated, Rahma's husband arrived and assumed care of the children at the apartment while she was still in the hospital. When Rahma was discharged home, she remained on respiratory home isolation for another two months before sputum smear specimens converted to negative.

TREATMENT

I have certainly had my share of cases where directly observed therapy (DOT) was rife with challenges. This family, despite its large number of individuals, was not one of those cases. DOT proceeded, for the most part, without unforeseen challenges. We knew we had a large number of children to treat and planned accordingly. At one point, we had a dozen children receiving daily DOT (mostly as part of window prophylaxis). After some discussion, we decided to convert an empty cubicle in the TB clinic into a makeshift pharmacy and developed a process for preparing medication doses. The medications needed to be crushed and mixed with food for administration. For efficiency, we tried to schedule all of the pediatric appointments toward the end of the workday. Prior to the visits, the nurse would prepare the doses. We purchased a hospital grade pill crusher, and each child's dose was crushed and placed in a clear plastic condiment cup with a label for that child. Next, the crushed medication was mixed with that child's preference of food: pudding, yogurt, applesauce, and frosting were all used. Over time, we learned that adding crushed cookie pieces to the food helped disguise the medication, and we discovered that Nutella was the most popular food vehicle. Once the medication was crushed and mixed, each cup was covered and packed for transport along with a plastic spoon. This system proved to be very efficient and made the experience as painless as possible for all involved.

OUTCOME

During treatment, Rahma became pregnant. She was concerned about the effects the medications might have on her unborn child. To address her concerns, I spent some time re-educating Rahma about the importance of treatment completion and the safety of the medications. Rahma continued treatment through her pregnancy but refused further treatment after giving birth quite prematurely. She completed 252 of 270 doses and the treating physician determined that she had been adequately treated (93% complete).

All of the children completed treatment with no problems. One person needed re-evaluation for TB infection. At the time of this writing, that individual is near the end of a nine-month regimen. Two other individuals refused treatment.

Public Health Nurse preparing pediatric doses of dissolved TB medication with preferred foods for DOT.

LESSONS LEARNED

As a "seasoned" public health nurse, I entered into this woman's situation thinking that I had a good understanding of Somali culture. I had extensive experience working

with Somali families and felt I had learned a lot through my experiences. I discovered in the first week of the investigation that I had a lot more to learn!

As part of a family-centered approach to TB care, relationship building at the onset is very important. In my experience, I have found that one way to promote a good working relationship is to discuss patient confidentiality immediately. Once introductions have been made and I explain my role in their health care, I bring up privacy rights with parents under my care. I do this before asking any questions. I also end the conversation by repeating the same information about privacy. Depending upon the individual, this method of reinforcing respect for privacy may need to be repeated at future visits. For TB contact investigations, I also try to be as transparent with the patient as possible, making them aware when I notify the family members, friends, and coworkers they identify as being exposed. This is a good opportunity to demonstrate honesty and openness with the patient, which can lead to developing trust.

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In my experience working with Somali families, as in many families from various cultures, I have noticed the physician is often held in high regard. For this reason, the physician is usually the first person I request written consent for release of information. This is my opportunity to inform the patient that I work in partnership with their physician, even though I work for the "government." This helps break down any fear of government or public health officials. One change I have made to my normal routine is to use phone language services rather than utilizing local interpreters for Somali families in our community. Sometimes using local interpreters causes concern for privacy. For this reason, I have switched to using the language line. Using the language line removes that barrier and helps to maintain patient confidentiality. The language line also allows me to have an interpreter on hand any time, which was very helpful in this case since I was visiting multiple homes every day. Scheduling an interpreter to join me for each visit would have been extremely difficult and resource intensive. Using the language line also allows for better eye contact and direct body language between the patient and myself. I have found this further promotes trust as part of the relationship building process.

I believe that the trust I established with the family from the onset allowed for the flexibility needed to complete DOT with the children. In some cases, I might expect parents or caregivers to prefer pediatric doses be prepared in the home under their supervision. For this case, with so many children, we discussed having to pre-prepare the doses ahead of administration. The patient and family members gave us approval to do this. I am sure having the medication doses already prepared prevented some anxiety for the children. Also, having the child choose the food item to be mixed with the medication and allowing them to feed themselves (if age appropriate) gave them a sense of control. These strategies contributed to the successful treatment outcomes.

One small challenge encountered in this case was around the concept of "time." As we know, not everyone in the world views time in the same way. The concept of time differs across countries and cultures. Many cultures have a more openly flexible concept of time than what is typical in the United States. Having worked extensively with the local Somali population, I expected to encounter issues with appointment times and punctuality, especially when making multiple home visits on a daily basis. I found it worked best if we made appointments for a time range, instead of a specific time. For example, we would plan for my daily DOT visit to occur during "after school time," or "in the morning," (which meant before 10 am). This provided me with flexibility to accommodate other appointments and obligations and it was a better fit for the patient's expectations. Many times, I would arrive at a patient's home and they were not there but at another family member's home nearby or at a relative's home I would be visiting later that day. It was fairly easy to manage those instances, and it was helpful that the entire extended family had embraced the importance of facilitating daily DOT appointments. Occasionally, patients would not be home during scheduled appointment times, and would not be available by phone. Those circumstances were more challenging to manage, and required additional phone calls and time to reschedule the appointment. If the frequency of these "no show" appointments increased with a particular family, I would mitigate the situation by making a reminder phone call every day, prior to the appointment.

In this case, some of the most interesting cultural lessons I learned surrounded the function of the family,

Tips for Pediatric Medication Administration

Working with parents or caregivers

Convincing parents to begin treatment of TB infection in their children can be challenging. Parents are often concerned about giving their outwardly healthy children medicine for extended periods of time, and are concerned about potential side effects. It is important to connect with the parents and establish rapport, while convincing them of the need for treatment for TB infection in their children.

- Emphasize that treatment for TB infection is a way to protect their child.
- Ask parents if they give the child vitamins, and explain that treatment for TB infection is a similar proactive way to keep their child healthy.
- Show parents the pills needed for treatment of TB infection daily as compared to the handful of pills needed for treatment of TB disease.
- Explain the options for treatment of TB infection and ask parents and the child about their preferences; many parents are concerned about the regimen length and may prefer shorter regimens; consult with the physician regarding preferences to select an appropriate regimen.
- Give parents clear instructions regarding medication administration and side effects. For example, if a child is vomiting, parents should skip the dose and call the nurse. Vomiting may be unrelated to TB medications, for example, due to a virus. If it has not been resolved the next day, the child should be brought to the doctor.

General Tips

- Involve parents in the planning and decision making.
- Assess the child's ability to take medications.
- Pay attention to timing, volume, and texture.
  - Administer the medication at the same time every day.
  - Administer the medication when the child is hungry.
  - Mix the medication with a small amount of the child's favorite food.
  - Distract the child while giving medication.
  - Try different techniques until finding one that works and make adjustments as needed.

Remember:

- Children generally tolerate medicine better than adults.
- Be quick, be pleasant, be firm!

both nuclear and extended. I was able to observe the benefits of extended family involvement. This was most evident as I observed the patient's children being cared for by multiple other families while Rahma was hospitalized and on home isolation. This included the patient's husband, from whom she was estranged. Family cohesion and connection clearly trumped any previous disputes or disagreements that may have occurred. Extended family members would take turns bringing food and supplies to the home every day while she was ill, despite the fact that there was a risk of exposure to TB during the time she was still infectious. We face and navigate many challenges in TB work. One of those challenges being family dynamics and sometimes, family discord. It was an enlightening experience to watch this family rise above that.

Tips for Administering Medications to Children Unable to Swallow Pills or Capsules

For babies and young children, the pill can be crushed.

The crushed pills can be dissolved in a teaspoon of water to avoid granules.

This can be mixed with a small amount of food such as apple sauce, mashed bananas, yogurt, or pudding. Using a small amount of food will ensure the child takes the full dose. Follow with plain food or liquid.

Somalia Brief Country Profile

Since the 13th century, Somalia, occupying the region known as the Horn of Africa has struggled with conflict. At different times, the country has either been occupied or acquired by Egypt, Britain, Italy and France. Despite being an almost completely homogenous region, where nearly all Somalis speak the same language, hold the same religious beliefs and eat the same food, there is no unified governing system in Somalia. Rather, Somalia is a clan-based society. In very general terms, Somali culture is made up of strong, clan-based social networks of large, multigenerational families. Clans are delineated through lineage and kinship ties, usually traced back to one male family member. This serves as a kind of hybrid legal system with a mix of common, civil, and religious law, which can vary across clans.

Today, after more than twenty years of civil war following the ousting of President Siad Barre in 1991, Somalis are struggling to establish a unifying governmental system to overlay this clan-based system. Most recently, members of Parliament elected Mohamed Abdullahi Mohamed President of Somalia in February 2017.

The years of conflict and volatile instability have left Somalia with one of the highest rates of child malnutrition and infant mortality in the world. The World Health Organization reports there were 14,381 new cases of TB in Somalia in 2016. According to the US Department of Homeland Security, there were approximately nine thousand arrivals to the US from Somalia in 2015. The United Nations estimates the number of Somali born individuals living in the US is roughly 150,000. The US states with the largest groups of Somali residents are Minnesota, Oregon, Maine, Washington and Ohio.

Resources for Pediatric TB Treatment

Treatment of Tuberculosis: Standard Therapy for Active Disease in Children: http://globaltb.njms.rutgers.edu/educationalmaterials/productfolder/treattubchild.php

Tuberculosis Handbook for School Nurses: http://globaltb.njms.rutgers.edu/educationalmaterials/productfolder/tbedusn2.php

What Parents Need to Know About Tuberculosis (TB) Infection in Children (available in English and Spanish): http://globaltb.njms.rutgers.edu/educationalmaterials/productfolder/tbparentschild.php

Tricks of the Trade: Strategies for Pediatric TB Case Management (webinar archive): http://globaltb.njms.rutgers.edu/educationalmaterials/aa/2016b.php

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The National Center on Cultural and Linguistic Responsiveness

Bridging Refugee Youth & Childrens Services Cultural Backgrounder
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This material was supported by the grant U52PS004090 funded by the U.S. Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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