TB & CULTURAL COMPETENCY

Notes from the Field

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Supportive Adjustment to a New Life Makes TB Care Possible

This issue highlights the story of a refugee family from Burma who is affected by TB. The story was shared by a local health department in the Northeast United States. Names and some details of the case have been altered to protect the identity of the patient.

As noted in Issue #2 of this newsletter (December 2004), refugees have particular needs and concerns in regards to health issues. Background information on Burma and some of the issues faced by refugees from this area are also highlighted in Issue #7 (Spring 2008).

This article is written from the perspective of the TB nurse case manager:

Young girl with malnourished brother at a camp for Rohingya in Sittwe, Myanmar. Photo: Tomas Munita/The New York Times

Our patient, Sufia Begum, was born in Burma, also known as Myanmar, and arrived to the United States (US) in June 2012 with her five children, including a 15 year old daughter and four younger siblings. Prior to arrival in the US, Sufia and her children were in a refugee camp. We do not know how long she and her family lived in the resettlement camp. Sufia's eldest daughter, Nasima, was pregnant when she arrived in the US, and had a baby a few months after her arrival. The family identified as part of the Rohingya ethnic group.

Soon after settling in the Northeast, Sufia became very ill and was admitted to the hospital where she was diagnosed with lupus. As a result of her illness, she missed many of the cultural education classes that were offered through the local refugee resettlement agency. These classes typically provide practical information such as learning how to take public transportation, arranging medical appointments, learning how to access shopping facilities, registering children in school, and connecting refugees with needed social support services. Many resettlement agencies also offer citizenship classes, English for Speakers of Other Languages (EOL) classes, job training, interpretation and translation services and driving lessons.

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TB Diagnosis

In May, 2013, Sufia was hospitalized again, this time with complaints of shortness of breath and nausea. A CT scan of the chest showed a cavity in the left upper lobe and miliary nodules, which raised concerns for either an infectious or malignant process. Sputum smears were negative for acid fast bacilli (AFB) and a bronchoscopy specimen was also negative. Sufia was started on Rifampin, Isoniazid, Pyrazinamide and Ethambutol (RIPE) by the infectious disease physician, based on the suspicion for tuberculosis.

When we first met Sufia in 2013, she was very sick. She had a medical history of respiratory, cardiac, renal and hormonal conditions, as well as depression, which pre-dated her arrival. At that time, she also had a feeding tube which was removed just prior to referral for TB care. Although Sufia had been sick since coming to the US, she did not show any signs or symptoms of TB at first. In fact, she was not diagnosed with TB until a year after her arrival.

The infectious disease physician in consultation with a pulmonologist felt that Sufia's symptoms and radiographic findings were more likely due to aspiration pneumonia instead of TB. Therefore, RIPE was discontinued until culture results were available to definitively rule out TB. We worked in close collaboration with the social worker to plan for hospital discharge and arrange for assistance with activities of daily living and child care. On June 4, 2013, Sufia was discharged on home isolation with a plan

Burma

Burma is a very ethnically diverse country with many different languages and cultural practices. Various ethnic groups were united into a single country during the British colonial period. Burma gained independence from the United Kingdom in 1948, but subsequently dealt with unrest and civil war for decades (Minetti, et. al, 2010). Human rights abuses by the government against non-Burman ethnic groups were common, and millions were displaced (CC Newsletter #7). After decades of military rule, a quasi-civilian government was elected in November 2010, and a democratically elected president was inaugurated in March 2016 (US State Department, 2016). Refugees from Burma have been steadily arriving in the US since 2006. In 2014, there were 14,598 Burmese refugees who arrived in the US, representing 20.9% of all refugees to the US (Department of Homeland Security, 2016).

Burma is also one of the 30 countries with a high burden of tuberculosis (WHO, 2015). In Burma, roughly 68% of the population is ethnically Burmese (SNTC, 2009). Other groups include 9% Shan, 7% Karen (multiple subgroups), 4% Rakhine/Arakanese, 3% Chinese, 2% Indian, 2% Mon, and 5% other (SNTC, 2009). A large number of people from these ethnic groups in Burma are now living in refugee camps in Thailand (Minetti, et. al, 2010). The ethnicity of the population within the refugee camps is about 80% Karen, 15% Karenni, and 2% Burman. Smaller numbers of Shan, Mon, Chin, Rakhine/ Arakanese, and Rohingya comprise the remainder of the population (SNTC, 2009). A tiny proportion of refugees resettled from Burma are Muslim (the Rohingya ethnic group). Most Muslims in Burma have a significantly worse experience as a minority group than refugees from Eastern Burma (Karen, Karenni, Chin, Mon, etc.). (Refugees International, 2008). Most Muslims in Burma are not allowed to be Burmese citizens, and are not recognized as a distinct ethnic group by the government (Refugees International, 2008).

Map of Burma. Image source: http://www.state.gov/p/eap/ci/bm/

In Burma, the official language is Burmese though many ethnic groups have their own language (SNTC,

for follow up by the local health department.

On July 19, 2013, we received a report of positive AFB, and the culture grew *Mycobacterium tuberculosis*. We contacted Sufia for a follow-up appointment in the clinic and informed her of the TB diagnosis. RIPE was re-started with arrangements for Directly Observed Therapy (DOT) in the home.

Sufia was not overly concerned about her TB diagnosis—possibly because she had so many other issues to deal with at the time. We provided TB education—what the diagnosis meant, how it would be treated and the continued need for home isolation for some time. Social stigma around TB also did not seem to be an issue perhaps due to acceptance within the community. Although Sufia was educated on the importance of wearing a mask to prevent the spread of infection to others, she did not like wearing one and wanted to have visitors in her home. Relatives wanted to visit because they knew she was sick. I emphasized to the family that there should not be relatives or neighbors visiting in the home, and if there were any visitors, they needed to wear masks. Our health department is fortunate to have factsheets on TB that have been translated into Burmese, which we shared with Sufia and her family to reinforce the messages. Sufia spoke Burmese but had limited literacy with written Burmese. We provided a lot of education on home isolation, and gave reminders every few days to make sure the family understood how important it was to be adherent.

2009). **It is important to remember that not all refugees from Burma speak Burmese**. Most of the persons in refugee camps speak, as their native language, one of three main dialects of Karen. Approximately 68% speak S'gaw Karen, 9% speak East Pwo Karen, and 4% speak Western Pwo Karen. About 15% of the refugee population speaks one of the dialects of Karenni. Other common languages spoken among refugees include Shan, Mon, and Chin (SNTC, 2009). Depending on their level of education, about 20% of the refugee population can speak Burmese, and less than 2% can speak English (SNTC, 2009).

In 2010, there were approximately 140,000 refugees living in camps in Thailand (Benner, et. al, 2010). Thirty percent of these refugees are youths between the ages of 15-24 years of age (Benner, et. al, 2010), and a large proportion of them have lived their entire lives in the camps before immigrating to the US. Individuals living in the camps have minimal access to the outside world and depend on the Thai government and international aid organizations for food, shelter, health services, and education (Benner, et. al, 2010). School is limited to ten years total learning and access to higher education and job opportunities are limited (Benner, et. al 2010).

Upon moving to a new country, newly arrived refugees have an overwhelming amount of knowledge and skills to learn, including a new language and adapting to a new culture and environment (Koh, Liamputtong, & Walker, 2013). This process can be exhausting, both physically and emotionally (Kenny & Kenny, 2011). Moreover, refugees may also be dealing with trauma prior to migration, whether in the camps or their original country.

It is important to note that every family is unique and that cultural practices can vary by household and generation. Use open-ended questions and get to know each family's unique characteristics and experiences.

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Immigrants and Refugees

Although these terms are sometimes used in everyday language, immigrant and refugee are legal terms that define the rights and opportunities of individuals have. An ***immigrant*** is someone who leaves his or her country of origin to take up permanent residence in another country. This may be someone who comes to the United States for a job, or to join family members. A ***refugee*** is someone who leaves their country and who has been officially registered by United Nations staff and then granted permission by another country to settle in that country after being forced to leave his or her home because of war, violence, or persecution based on race, religion, nationality, political opinion or membership in a social group defined by religion, identity or gender. These circumstances force millions of people to leave their homes, but do not qualify them to be legal refugees. There may be particular health needs and concerns when working with a refugee population.

Sources:

Adapted from:
CC Newsletter, Issue #7, 2008. Available at http://globaltb.njms.rutgers.edu/downloads/products/Newsletter%20(Spring%2008).pdf

The UN Refugee Agency, What is a refugee. Available online at http://www.unrefugees.org/what-is-a-refugee/.

Resources for working with refugee/immigrant families:

Bridging Refugee Youth and Children's Services (BRYCS) has the best collection of cultural competence resources designed for clinical and social service staff working with refugee families
http://www.brycs.org/clearinghouse/Highlighted-Resources-Child-Welfare-Training-Curricula-for-Staff-Working-with-Refugees-and-Immigrants.cfm

Best Practices Guide for Working with Families from Refugee Backgrounds in Child Welfare (two page summary)
http://cascw.umn.edu/wp-content/uploads/2016/05/BestPractices.pdf

NRCFCPP Information Packet: Cultural Sensitivity with Immigrant Families and Their Children (toolkit)
http://www.hunter.cuny.edu/socwork/nrcfcpp/downloads/cultual-sensitivity-with-immigrants2.pdf

Bridging Gaps through Interpretation

Another advantage of our health department is that we had the resources to hire a part-time medically trained interpreter, Kay, who speaks Burmese. In addition to language interpretation, Kay assisted in the translation of documents and forms, and overall served as a cultural broker. Kay's role at the health department involved providing interpretation and translation services, DOT visits in the field, patient appointment reminders, and transportation arrangements for patients when needed.

As a member of the Burmese community, Kay was familiar with many of the cultural and religious traditions and she helped to fill in these gaps. Kay's knowledge, general approach and standing in the community were truly assets in this situation. One example of Kay's role in this case was during Ramadan, when Muslim patients who are fasting may not be able take their TB medications until after sundown. Kay made special arrangements and provided DOT after the patients had broken their fast, sometimes at 9 pm.

Since Kay also lives in the community, she serves as a resource person. Sometimes individuals knocked on her door at night with questions or concerns. She would then call me and we worked together to address the community's needs. In Sufia's case, she frequently called Kay with questions about dealing with her landlord and requested help with completing necessary paperwork to obtain WIC benefits.

Case Management and Interpreter Team

Patients can pick up on the relationship between myself and Kay. They can see we have a relationship of mutual respect and collaboration. We are a team; one person's job is not more important than the other. This relationship is missing when one uses the telephone for interpretation, and I think it gives patients confidence in our team, building a lasting rapport.

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Kay reflects on some lessons learned over the years. She says "some patients may be afraid to ask questions, and it's important to encourage them to ask questions and not be afraid. If the patient feels shy to raise certain issues, they may feel more comfortable if the interpreter offers to bring them up instead." Kay recommends interpreters should be familiar with the health department and TB program as well as the types of resources and services that are available in the community. She believes it is helpful to be able to have experience and resources to share, rather than just interpreting words. Kay further shares that interpreters should realize that education is going to be necessary, and figure out the best way(s) to deliver the message.

The Rohingya

The Rohingya are one of Burma's Muslim minority groups residing in the Rakhine state. They are reported to be descendants of Arab traders and other groups who have been in the region for generations. The Rohingya people are considered "stateless entities," as the Burmese government refuses to recognize them as one of the ethnic groups of the country. For this reason, the Rohingya lack legal protection from the Burmese government, are regarded as mere refugees from Bangladesh, and face strong hostility in the country—often described as one of the most persecuted people on earth.

About one million Muslim Rohingya are estimated to live in western Rakhine state, where they are a sizable minority. An outbreak of communal violence there in 2012 saw more than 100,000 people displaced, and tens of thousands of Rohingya remain in decrepit camps where travel is restricted. To escape the dire situation in Burma, many Rohingya have turned to smugglers, choosing to pay for transport via boat out of Burma to escape persecution. Fleeing repression and extreme poverty, more than 88,000 migrants took to sea from the Bay of Bengal between January 2014 and May 2015, according to the International Organization for Migration (IOM). Regionally, no unified or coordinated ASEAN (Association of Southeast Asian Nations) response has been proposed to address the deepening crisis.

Sources:

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Woman at hut in Rohingya camp outside Sittwe, Myanmar. Photo: Tomas Munita/The New York Times

Legal Complications

A few months into her treatment, we learned that Sufia's oldest daughter, Nasima, had been married prior to her arrival in the US. Nasima was considered an adult in her culture so this was considered the norm and both sets of parents had given consent to the marriage. We are not sure if she had been married while in Burma or when living in the refugee camp. Nasima's husband was not able to make the journey to the US. During our home visits, we became aware that Nasima, who was now 16, had been looking after her infant and also her four siblings when they were not in school. Sufia did not realize that this could become a problem since Nasima should also have been in school. We called the discharge planner and the assigned case worker from the Refugee Center to discuss the need for adult supervision while Sufia was in the hospital.

My goal was to treat everybody as if they were someone in my family – with dignity and respect.

While on home isolation, Sufia was still too ill to look after her family. Child Protective Services was alerted to this situation by an anonymous caller. The Director of Clinical Services at the health department was then contacted about placing the children in foster care. It was important for the children, and it was a priority for me, that they were not taken away from Sufia. My goal was to treat everybody as if they were someone in my family – with dignity and respect. We contacted a friend of the family who lived in the community and who agreed to assist with child care. I also reached out to a contact at the Legal Aid office for assistance and they were able to help. We obtained the necessary paperwork for a family friend to apply for temporary guardianship and I explained everything to Sufia with Kay's interpretation. Together, we helped Sufia understand the process and she signed the appropriate releases. We referred Sufia to a pro bono attorney at the Refugee Center regarding the Child Protective Services issues and the charge was eventually dropped.

We also learned that Sufia was encouraging Nasima to find a spouse to help support and take care of the home and younger children. Shortly thereafter, Nasima met a 21 year old man who she wished to marry. We referred Sufia and her family to a case manager from the community for education about legal issues and US laws that apply to the age of consent for marriage. It was clear that the family was not aware of how their culturally acceptable practices may be prohibited in the US. I explained to Nasima and the young man that it would be illegal for them to have a relationship and they agreed to end it.

Another priority was ensuring that the children did not miss school. I visited the house regularly to check on the entire family, not just Sufia. For the first two months, it was pretty rough and after 90 days, the resettlement agency no longer provided case management to Sufia and her family. However, we still saw her over the course of her treatment and could share information and resources.

Coordinating Care

With all of her health issues, Sufia needed to see many specialists. We coordinated appointments with various doctors, including a pulmonologist, cardiologist and rheumatologist. However, some of the specialists noted she frequently missed appointments. When we discussed this with Sufia, she stated that she only visited the doctor when she was sick in Burma and she did not understand the need for so many doctors. I explained that if she missed appointments, the doctors may not want to see her again and asked her to call me if she needed to cancel or reschedule an appointment. I called several of the specialists and explained the situation, asking them to be patient with her. I want patients to have the tools to take care of themselves when no longer receiving care from the health department. They need to be successful advocates for themselves.

"I want patients to have the tools to take care of themselves when no longer receiving care from the health department. They need to be successful advocates for themselves."

Sufia could not read English but could read some Burmese, so we worked together on a color scheme to help her distinguish the TB medications. I requested the pharmacist to place a red sticker on her nausea medication, so she would know to take the red sticker medicine an hour before her DOT appointment. She was also on a medication for a rash, and the pharmacist placed a green sticker on that bottle. I made a color-coded calendar for her, with each month filled out. Her medical appointments were shaded yellow, her DOT days were another color and her children and grandchild had different colors for their appointments. I also worked with her to teach her how to read a prescription label, which was important for taking all of her medications as prescribed.

Contact Investigation

The TB contact investigation turned out to be the most straightforward part of this case. Kay played a key role during the TB contact investigation process, both for identification of contacts and conducting interviews with the contacts. Kay asked the family who visited the home during recent religious holidays that were celebrated within the community. This information was useful for identifying contacts that we otherwise may have been unable to elicit because we were not familiar with these holidays.

We tested all the kids and several of the family members and friends who had visited the home during time period that Sufia was infectious. All of the contacts we tested were negative on initial and repeat testing, so there was no need to expand the contact investigation. However, we placed the infant on 8 weeks of window prophylaxis treatment as a contact to an active pulmonary TB case. After 8 weeks, the infant tested negative and treatment was discontinued.

Conclusions and Reflections

Sufia was treated for a total of nine months. Once she completed treatment, we informed the other specialists under whose care she remained. She was referred to a community social worker to assist her with any needs in the future. She is now healthy and cured of TB, though she and her family continue to face many challenges as they adapt to their new life in the US.

This was a challenging case—there was never a dull day. It was an intense case requiring a lot of energy. The experience reminded me how important it is to think outside the box. We really had to be creative to address barriers and ensure Sufia's adherence to treatment for TB and other illnesses. The color-coding system and planner we developed for her and the family were helpful in a way that was simple and easy to use. It was imperative to help Sufia become self-sufficient because we would no longer a part of her life once TB care and treatment were complete. Teamwork was also essential—my relationship with Kay and her willingness to go above and beyond her role as interpreter improved our care of Sufia.

"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."—Maya Angelou

What is Health Literacy?

Literacy, numeracy, and technology skills are increasingly important in today's information-rich environments. What people know and what they do with what they know has a major impact on their life chances. For example, people with low literacy proficiency are more likely than those with higher literacy skills to report poor health.

Health literacy is the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.

Anyone who needs health information and services also needs health literacy skills to:

- Find information and services
- Communicate their needs and preferences and respond to information and services
- Process the meaning and usefulness of the information and services
- Understand the choices, consequences and context of the information and services
- Decide which information and services match their needs and preferences so they can act

Anyone who provides health information and services to others, such as a doctor, nurse, dentist, pharmacist, or public health worker, also needs health literacy skills to:

- Help people find information and services
- Communicate about health and healthcare
- Process what people are explicitly and implicitly asking for
- Understand how to provide useful information and services
- Decide which information and services work best for different situations and people so they can act

The U.S. Department of Education defines adult literacy and numeracy in terms of skills that help people accomplish tasks and realize their purposes. Researchers can measure literacy and numeracy skills, but skills are not static. People can build these skills, and even adults with limited skills can get better results when their environments accommodate the skills they have.

Sources:

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CDC Learn About Health Literacy. Available at http://www.cdc.gov/healthliteracy/learn/index.html

Cultural Broker Role

by Stephanie Spencer, M.A.

Cultural broker is an additional role that some interpreters may fill, and it is also a role that other community members, health care or community organization staff, and others involved with patients, families and caregivers can play.

The National Center for Cultural Competence defines four possible roles of cultural brokers and describes the goals of cultural brokers as a:

1. Liaison
2. Cultural guide
3. Mediator
4. Catalyst for change

Cultural brokers may not necessarily be members of a particular group or community. However, they must have a history and experience with specific groups for which they serve as broker including:

- The trust and respect of the community;
- Knowledge of values, beliefs, and health practices of cultural groups;
- An understanding of traditional and indigenous wellness and healing networks within diverse communities; and
- Experience navigating health care delivery and supportive systems within communities.

Whatever their position, cultural brokers aim to build an awareness and understanding of the cultural factors of the diverse communities they serve and of the ways in which such factors influence communities.

Source: http://nccc.georgetown.edu/culturalbroker/2_role/index.html

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