Unit 6: Living with TB Today
Activity 4: Case Studies – comprehension and application

Description:
Students will read case studies of people and families who have been affected by tuberculosis and will answer questions that test their comprehension of the readings. Each student may be asked to complete one or more of the four provided case studies, or students may be divided into four groups that are each assigned one case study to complete.

Time: Activity Sheet: 30 minutes + 15 minutes review

Objectives:
- To demonstrate reading comprehension.
- To learn about the personal experience of one individual or family with TB.
- To understand some of the difficulties to receiving TB treatment in different locations around the globe.

Curriculum Links:

Reading	1. Reading for Meaning	1.4 demonstrate understanding of a variety of texts by summarizing important ideas and citing supporting details
		1.6 extend understanding of texts by connecting the ideas in them to their own knowledge, experience, and insights, to other familiar texts, and to the world around them
		1.8 make judgements and draw conclusion about the ideas and information in texts and cite stated or implied evidence from the text to support their views

Materials:
Handout

Procedure:
1. Provide students with the worksheet(s) and ask them to complete it individually or in groups.
2. Review the work-sheet with the students and clarify any common misconceptions.

Background Info:
Living with TB Today

One third of the global population has been infected with tuberculosis. Though some will be able to fight off the infection themselves, many will develop cases of active tuberculosis. Roughly one person is infected with TB every second and one in ten people infected will develop active TB. There were 9.4 million new cases of TB in 2009.

Side-Effects of TB Drugs

In many communities a tuberculosis diagnosis is considered a death sentence, though it need not be. Some patients can be treated in their homes and continue to live a normal life while on TB medications, while others must be treated in hospital.

The drug regimen used to treat TB involves a cocktail of tablets and injections that must be taken for between six months and two years. Patients will take as many as twenty tablets a day (and possibly more!) depending on the type of TB they have been diagnosed with, for up to six days a week. The side effects of these drugs are serious. Gastric problems, diarrhea, headache, loss of hearing, and liver or kidney dysfunction are but a few of the common problems that arise because of TB treatment.

> "I get terrible headaches, dizziness and loss of appetite. It is better now, but there were times in the past when I just wanted to die, I felt so low and depressed. Maybe it was the drugs, or maybe the length of treatment, but it all just seemed too much."
>
> "It's not easy taking all the drugs. I take two tablets for my TB every morning at 6 am and then for my HIV I take one in the morning and three at night. I get pains in my legs and headaches and sometimes I just don't want to take the drugs, but I do my best."

Quoted in Medecins Sans Frontieres, "Tuberculosis: New Faces of an Old Disease" (23 March 2009) *align right (?) and make previous a hyperlink to < http://www.doctorswithoutborders.org/publications/article.cfm?id=3507>

Drug Resistant TB

Because of these debilitating side effects and the length of treatment programs, some people choose to end their TB treatment early. This can lead to drug-resistant strains of the bacteria, strains that do not respond to most available treatments. Drug-resistant strains can develop within a person infected with TB, or be passed on to infect a new person. New treatments plans for multi-drug resistant (MDR-)TB are available, but they take several years to complete and cost much more than drug-susceptible TB treatment plans.

In 2008 an estimated 440,000 cases of MDR-TB existed worldwide. An estimated 3.3% of all newly diagnosed TB cases had MDR. 150,000 people died from MDR-TB in 2008.

In an attempt to maximize treatment success and limit treatment dropout and the development of MDR strains, the World Health Organization endorses the DOTS (Directly Observed Therapy Short-course) strategy. Under this program, patients take their medication while supervised, ensuring compliance with their treatment plan. In practice, though, daily supervision is difficult to enforce and the strategy is often modified to better fit the specific conditions of the location and patient.

HIV/AIDS & TB

A significant number of new TB cases are people with HIV whose weakened immune system cannot contain TB. The correlation between HIV and tuberculosis is staggering; being infected with either disease makes you more susceptible to the other. In developing countries, TB is the leading cause of death among people who are infected with HIV; up to 50% of deaths of HIV patients are due to TB. In more industrialized countries, about 10% of HIV patients also have TB.

Multiple drugs are required to treat both TB and HIV. Some cause negative interactions and some drugs used to treat one disease diminish the efficacy of those taken to treat the other. An integrated treatment plan is necessary for a cure.

The social consequences of TB

There is a great social stigma attached to TB. Afraid to contract the disease, many people avoid those with TB, isolating them within the community. This is particularly true of people with MDR-TB. Additionally, many TB patients must travel outside of their home communities to obtain treatment. Beyond the loneliness of this separation from family, the financial strain of travelling to clinics is often difficult to bear when a wage-earner is too ill to work.

Some countries (or states and provinces) approve the detention and isolation of people with active TB in an effort to limit the spread of disease. Infectious patients who do not comply with treatment plans or, in some cases, who are perceived to be a future threat of non-compliance may be detained in the custody of health officials. Those in favour of this policy argue that it enforces the patients' social responsibility when they prove unwilling to do so voluntarily, while those opposed to it argue that detention violates patients' human rights.

The cost of living with TB goes beyond physical discomfort and pain. Many patients suffer the mental pain of isolation, the guilt of not providing for their families, and the stress of poverty. Improved medical treatments that tackle the problems of HIV and drug-resistant TB are needed, as are social programs that respond to the social and pyschological consequences associated with the disease.

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ANSWER SHEET: Case Studies – comprehension and application

Robert David (Haiti)

In 1986, when Robert David was 19, he complained of cough, night sweats, and fever. Initially he used herbal remedies to try to get better, but Robert went to hospital when his conditioned worsened and he lost weight and experienced shortness of breath. There, he was diagnosed with tuberculosis and prescribed two medications to take. In order to receive this treatment Robert had to commute for two hours from his home to the hospital, and often had to wait at the hospital for hours before being seen by a doctor.

In 1987 Robert was able to switch to a clinic closer to his home. He was prescribed three anti-TB drugs (isoniazid, ethambutol, streptomycin) for an 18 month period. It was very difficult for Robert to acquire his medications because of their cost; his family sold half of their land in order to pay for the drugs. Robert stopped this treatment in 1988, but continued to be sick.

In 1990 Robert was treated in a sanatorium for 6 months in Port-au-Prince, where he took the medications isoniazid, ethambutol, pyrzinamide, and rifampin. After six months he was released and told to continue this treatment for 8 more months, then to take isoniazid and ethambutol for two more months. Ultimately, Robert was unable to acquire many of his medications because of political instability in the country. His symptoms persisted, and in 1992 he was readmitted to a sanatorium and treated with thiazina. His treatment was inconsistent, though, because political upheaval meant that medications were often not available.

In 1993 Robert went to the Clinique Bon Sauveur reporting chronic cough, night sweats, and weight loss – he weighed 110 lbs. Robert was prescribed multiple TB drugs. He complained of buzzing in his ears and nausea, but was very motivated to continue his treatments. A sputum sample was collected in summer 1994 and tested for drug-sensitivity. The test showed that Robert's TB was resistant to five of the main TB drugs. The drugs that would work against his TB were not available in Haiti and had to be specially imported by the clinic. Once Robert was on these drugs his condition improved greatly – he gained weight and was able to breathe more deeply. Improvement was short lived, though, and soon his condition began to deteriorate once again. Robert died in December 1995.

Case study summarized from Paul Farmer, "Social Scientists and the New Tuberculosis," pp. 174-194 in Partner to the Poor, ed. Haun Saussy (Berkeley: University of California Press, 2010).

1. What signs and symptoms of TB did Robert express?

   cough, night sweats, fever, weight loss, shortness of breath

2. What treatments did Robert receive for his TB?

Anti-TB drugs (isoniazid, ethambutol, streptomycin, pyrzinamide, rifampin, thiazina)
Sanatoria care

3. What difficulties did Robert face obtaining treatment for his TB?

   Distance to clinic
   Cost of medications
   Availability of medications (political instability & meds for drug-resistant TB not common – need to import)

4. What side-effects did Robert experience from TB medications?

   Buzzing in ears
   Nausea

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Blanca (Peru)

Blanca first thought she might be sick with tuberculosis when she began coughing in 1995, but did not seek out treatment because she afraid to find out the truth. She lived with her husband in the home of her mother with six of her siblings. Four of her siblings had already been diagnosed with TB.

Blanca was diagnosed with tuberculosis at age 22 after a sputum sample tested positive for the tuberculosis bacillus. Even though her siblings, from whom she had likely contracted the disease, had been shown to have drug resistant TB, Blanca was prescribed the standard 6-month treatment regime of 4 TB drugs. After one month of treatment, instead of improving Blanca's x-rays showed that her condition was worsening. Local health workers took a sputum sample and sent it to be tested for drug-susceptibility. Tests revealed that her TB was resistant to isoniazid and rifampin, the two most powerful TB drugs. Despite this, Blanca was told by health authorities that she needed to complete her prescribed course of treatment, even though at this point the prescription was to take the two drugs to which she had been shown to be resistant! Unsurprisingly, Blanca's condition continued to deteriorate and when she finished her course of treatment she was experiencing fevers, coughing up blood, and weighed only 80 lbs.

At this time, Blanca was prescribed a range of second-line TB drugs that her TB should have been susceptible to. These drugs were not included in the public health program, though, which meant that Blanca had to pay for them herself – a cost of $200 a month. Despite her entire family pooling their resources, they were only able to come up with enough money to pay for one week's worth of medication! Blanca knew that it would be impossible to continue the treatment for the months that were prescribed.

Several months later, Blanca finally received the necessary medications from the community health organization, Socios en Salud. Soon, test showed that TB bacteria were no longer present in Blanca's sputum – she was getting better! But, after being treated with inappropriate medications for so long, Blanca's TB was now resistant to five drugs instead of the initial two.

Case study summarized from Paul Farmer, Infections and Inequalities, pp. 235-240 (Berkeley: University of California Press, 1999).

1. What methods did health workers use to identify Blanca's illness?

   Sputum sample tested
   X-Rays

2. Why did Blanca not get better when she was first treated for TB?

She was given the treatment for standard, drug-susceptible TB. Since her siblings had been shown to have MDR-TB, doctors should have tested Blanca for drug resistance prior to prescribing a course of treatment.

3. What challenges did Blanca face to receiving the appropriate TB medications?

   Blanca was made to complete the standard course of medications even after she was shown to have MDR-TB – this would only increase the resistance of the TB bacteria.
   The high cost of second-line TB drugs that are more effective at treating MDR-TB.

4. What could the health care system have done differently to minimize the development of Blanca's drug-resistance?

   Recognized the likelihood of her drug-resistance based on patient history.
   Responded to her diagnosis of drug-resistance by changing the treatment plan.
   Subsidized costs of second-line TB medications.

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Jean Joseph (Haiti)

When Jean first started to cough, he tried to get better by drinking herbal teas. When his cough only got worse, he decided to go to a TB hospital in Port-au-Prince because he knew they had x-ray machines there. Test results showed that Jean did have TB, and he was prescribed four anti-TB drugs.

Jean did not get better. He kept coughing. After he coughed up blood, a specialist referred Jean to a sanatorium where he was treated for three months. Even though he took the prescribed medication under the Directly Observed Therapy program Jean did not improve. After he had taken the medications for over a year and not gotten any better, Jean stopped taking the drugs and went to a herbal doctor. This did not work either, and Jean reentered the sanatorium shortly afterwards.

Jean was told that he would need to take different drugs that would work better on his drug-resistant TB. In order to pay for these more expensive drugs, Jean's family began to sell their furniture, farm animals, and land. Jean improved on these drugs and was able to return home. After five months of treatment, though, Jean's family could no longer afford to buy the necessary medications. After stopping the treatment Jean's TB returned.

Soon his three sisters and brother were also coughing. They were given the normal treatment for TB but did not improve. A nurse, suspecting that Jean and his siblings had drug-resistant TB, sent a sputum sample away for drug-susceptibility testing but Jean was never given the results of the test.

One day Jean heard about another TB clinic where drug-resistant patients were being treated. He brought his family to the clinic to be treated. After all being placed on the correct regimen of medications for drug-resistant TB, the whole Joseph family tested negative for TB.

Case study summarized from Paul Farmer, "The social impact of multi-drug-resistant tuberculosis: Haiti and Peru," in The Return of the White Plague, pp. 163-177 (New York: Verso, 2003).

1. How did health workers figure out that Jean had TB?

   X-Ray

2. What treatments did Jean try in order to get better?

   Herbal remedies
   Anti-TB drugs – first and second line
   Sanatorium treatment

3. What challenges did Jean face to receiving medication for his drug-resistant TB?
   His drug-resistance was not initially recognized and he was treated with medications that did not work.
   Cost of the second-line medications that would work.

4. Why do you think Jean might have tried herbal remedies to get better?

   More accessible than clinics – distance and cost.
   Religious connections?

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Corina Bayona (Peru)

Corina lived with her husband, son, daughter-in-law, and grandchild in a one-bedroom house in a slum north of Lima. When Corina started coughing she tried herbal remedies to cure herself because the closest medical clinic was closed by the time Corina had returned home from work. When her cough got worse she finally saw a doctor. He took a sputum sample that showed an active TB infection. Corina began the standard TB therapy of four anti-TB drugs and seemed to get better.

Corina began coughing again. She did not want people to know she was sick because of the stigma of having TB, so she started receiving treatment from a private clinic. This cost a lot more than public treatment, though, and soon Corina could only afford to buy two of the four medications she was prescribed. Corina kept getting sicker and had to stop working.

Now, Corina no longer responded to the standard medications used to treat TB. A doctor recommended that she go into a hospital. Corina went to a private university teaching hospital, but she was unable to pay for supplies. She then went to the public hospital, where Corina was told that she had to supply her own syringes, gloves, and gauze. Then, hospital workers went on strike and Corina was unable to receive any treatment at all. When the strike ended and she went back to the hospital to receive her medications, a doctor rudely told her that it was her fault that she had not completed her treatment and he sent to her another hospital in her neighbourhood. A doctor there was also unwelcoming and told Corina to go back to her local health care clinic.

Corina returned home and suffered from TB for three years. She sought help again after coughing up blood. Test results now showed that she had drug-resistant TB; yet, the doctors prescribed her the drugs to which she had just been shown to be resistant!

Eventually Corina heard about drugs that would work on drug-resistant TB. It would cost 500 soles a month to pay for these drugs, and the family was unable to produce this amount of money. When a community-organization was finally able to provide the medicines to Corina for free, it turned out that she had a bad-reaction to them and was unable to take them. Corina died of her tuberculosis.

Case study summarized from Paul Farmer, "The Consumption of the Poor," in Partner to the Poor, ed. Haun Saussy, pp. 222-247 (Berkeley: University of California Press, 2010).

1. How did the stigma of having TB affect Corina and her treatment?
   Sought out private care, which costs more. Corina could not afford the entire prescription, which ultimately caused the development of drug-resistance. Doctors seemed to blame Corina for her own illness and treated her badly.

2. Why do you think Corina developed drug-resistant TB?
   Was unable to take the full treatment prescribed – 2 of 4 drugs
   Treatment was interrupted when hospital went on strike.
   Was prescribed drugs that she was resistant to.

3. What problems can you see with the care that Corina received?
   Rudeness of doctors
   Hospital care suspended when staff went on strike
   Cost of appropriate medical care