

A Look into the Realities and Complexities of Tuberculosis as Observed Amongst Zulu Populations of Durban, South Africa

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In the global health field we place particular emphasis on infectious diseases, which have challenged the health of societies across the globe for much of history. Infectious diseases—most notably HIV, tuberculosis (TB) and malaria—have reached alarming levels and become a public health priority. While most infectious diseases are fundamentally similar in the fact that they can spread quickly, they affect different populations in a variety of ways. It is a global health necessity to understand both the cultures of the countries in which infectious diseases are common as well as the ways in which these infectious diseases affect the individual cultures in order to address effectively the challenges that people are facing. This paper focuses on TB, specifically drug-resistant tuberculosis (DR-TB). I have used my experiences with TB and Zulu populations in Durban, South Africa, to compile some of the most notable challenges the disease is posing to the population and KwaZulu-Natal health system today.

According to the Center for Disease Control and Prevention, one third of the world's population is infected with TB, and in 2012 alone there were 8.6 million incident cases and 1.3 million deaths due to the disease.¹ Globally, 3.6% of new cases and 20.2% of previously treated cases are multi-drug resistant. Additionally, South Africa is one of six countries detecting nearly 100% of diagnosed TB cases as drug-resistant.¹ Understanding the symptoms of TB is crucial for detection and diagnosis of the disease. Symptoms depend on the location of active TB bacteria in the body, but inactive TB does not produce symptoms.² The most common symptoms associated with TB of the lung include a chronic, sputum-producing cough (more than 2 weeks), dull chest pain, night sweats, weight loss and a low-grade fever.³ A skin test is encouraged if symptoms persist for more than two weeks. After a positive skin test, diagnosis can be completed through chest x-rays or sputum tests.³ TB can be diagnosed as either sensitive or drug-resistant. Once a patient is diagnosed with TB, the patient is tested for resistance to various TB drugs in order to create an individualized treatment regimen. Patients are usually started on a two-month regimen of a combination oral chemotherapeutic drug called Rifampin, whose components interact to induce and inhibit the metabolic activity of certain enzymes in the body. Those who are resistant to any drug in this combination are considered to have multi-drug resistant (MDR) TB. MDR-TB patients are instead given some combination of aminoglycoside, or antibiotic, treatment. If the patient is also resistant to these drugs, the patient is diagnosed as an extreme-drug resistant (XDR) case.

As early as 460 BCE, there have been accounts of tuberculosis fatally impacting large portions of populations around the world.³ Prior to European colonization in the mid-17th century, however, TB was not a large problem in South Africa. After colonization, the disease spread rapidly because of drought, war, mining, recession and the use of South Africa as a health resort for Europeans' TB

treatments created ideal conditions for spreading TB and restricted the country's resources to counter it.³ Despite having dealt with TB for so long, health professionals are still struggling to reduce the burden of this disease both in South Africa and on a global scale. Currently, South Africa has the third highest TB burden behind China and India, countries with much larger populations,⁴ and has the fifth highest drug-resistant TB rate globally. To put this in perspective, in KwaZulu-Natal in 2010, there were 2,032 MDR cases and 201 XDR cases.⁴

The burden tuberculosis places on the healthcare system has proven crippling to South Africa. The high number of patients who need treatment and attention is straining the workforce, and the economic burden of paying for treatments is also considerable. Despite DR-TB forming only a small proportion of the total case burden, it consumes a significant and disproportionate amount of the country's annual TB budget.⁵ Although DR-TB only accounted for 2.2% of the disease burden, it drained 32% of the approximate US\$218 million budget.⁵ A large portion of the budget is spent on XDR-TB cases because each case of XDR-TB costs US\$26,000, compared with less than US\$7,000 per MDR-TB case and less than US\$300 per sensitive TB case.⁵ This expenditure can and should be reduced using proper promotion and control methods, such as the creation of a decentralized treatment model in which smaller institutions are responsible for the planning and implementation of DR-TB treatment, and hospitalizations are reduced by providing more TB treatment in local clinics. South Africa has attempted this structure with their referral system, which requires a referral slip from a clinic in order to be treated at a hospital or specialized healthcare center. Despite its efforts to relieve the burden on higher institutions and localize treatment, this method has not shown consistent efficacy. Local clinics, especially in rural areas, do not always have the resources or staffing needed to support their catchment area, leading to long lines, lack of access to medication and overall patient frustration. As a result, patients do not seek treatment until they develop urgent cases and need to be hospitalized, thus undermining the original purpose of the decentralized system.

During the spring of 2013, I completed a medical internship in which I studied the prevention and treatment methods used to address DR-TB in the KwaZulu-Natal province of South Africa. Throughout the internship I learned about the disease burden of TB and the various challenges health professionals are facing while combating the disease within the context of the Zulu population of Durban, South Africa. These experiences and observations amongst Zulu populations of South Africa can be generalized to understand and address the TB burden on other South African populations and even other populations being affected by TB around the world. The facility in which I conducted my internship was Friends of the Sick Association (FOSA) TB Hospital in Newlands West, just

outside the city of Durban, South Africa. FOSA TB Hospital is an MDR and XDR specialized step-down facility, meaning that it lies somewhere between an emergency hospital facility and a normally staffed in-patient facility. Since its establishment, FOSA TB Hospital has worked hard to understand and help combat the TB epidemic, which has become a mainstay in KwaZulu-Natal. The daily challenges associated with this epidemic include insufficient diagnosis, HIV co-infection, treatment of side effects, defaulting from treatment and the emergence of pediatric TB.

Insufficient diagnosis

Insufficient preventative and diagnostic practices have contributed to the increase of the disease burden to its current level and severity. Poor prevention strategy and control of drug-sensitive TB has allowed for the spread of drug-resistant TB, as individual sensitive cases can mutate into drug-resistant cases if not treated. The overall level of TB bacteria remaining in the population without treatment has increased the likelihood of mutation, therefore allowing an increase in drug-resistance. While the Department of Health establishes prevention as the key to effective control of DR-TB, there have not been enough changes made to enact actual prevention strategies.⁴ In the words of one of the doctors at FOSA Hospital, "It's like the horse has bolted and now you want to go catch it. What you should have done is closed the stable door." The implementation of preventative policy is necessary for addressing the rapid spread of TB in South Africa. In the United States, each state government is responsible for establishing and regulating TB control laws and programs effective for their state.⁶ If South African provinces were to adopt similar responsibility, the country could be more successful in addressing TB control and prevention. At the least, it would be held legally responsible if the province continued to fall short of necessary TB management policies.

Many people are not being diagnosed soon enough, causing the initiation of treatment to be delayed. The more the disease is able to progress and multiply in the body, the more rigorous the treatment process needs to be. The TB treatment regimen is already extremely demanding, and delaying the initiation of treatment will further complicate the treatment. Diagnosis accuracy is also a problem for developing a treatment regimen. If the presence or resistance of TB is not properly diagnosed, treatment will be improperly supplied or simply not supplied. During my experience in the hospital, many patients admitted to the hospital had diseases that had already progressed to a dangerous state. Had these patients received treatment earlier, the prospect of their improvement would have been much better. More active public health surveillance, with active community level diagnostic and treatment techniques by local healthcare providers and community health workers, could improve early diagnosis and more prompt initiation of treatment. It is clear that diagnosis alone is insufficient to motivate patients to seek treatment. Therefore, if we put the responsibility on local health professionals, there may be hope for improvement.

One possible explanation for the insufficient diagnosis could be a tendency of many Zulu people to use traditional healers, known as sangomas, when they become ill. This is particularly common among more rural Zulu populations, whose access to healthcare is limited. These sangomas are a major part of the Zulu tradition, but they may be unable to diagnose and treat TB successfully. Traditional healing practices are inadequate for treating infectious diseases such as TB and therefore would only delay the implementation of proper treatment. While sangomas are instructed by the state to refer any suspected TB patients to a local clinic, there are no guarantees, as there is no follow-up on the patients regarding whether they actually go to an alternative provider. While this traditional practice is problematic, South African health professionals have made some efforts to intervene and utilize traditional healers as a promotional or educational tool, rather than a detriment. When visiting one sangoma in KwaZulu-Natal, I noticed she was wearing a "STOP TB" health promotion shirt. This shirt could imply that this sangoma had been educated about TB care and promotion, suggesting a certain level of communication and coordination between local traditional healers and national

organizations in the fight against TB. Another sangoma admitted she does not try to treat any patient displaying symptoms of TB, although she had been educated about the signs and symptoms of TB by a local health worker. While these cases do not prove the presence of improvements in TB diagnosis or treatment, further coordination between state health institutions and traditional healers could improve both the control and diagnostics of TB among Zulu populations. Encouraging sangomas to keep in contact with patients could help determine if those patients are taking their advice and going to clinics for proper treatment. Similar to the referral system, sangomas could require a proof of TB treatment from a clinic before seeing a patient. If the problem persists, South Africa could consider providing TB treatment and medication schedules to sangomas. If health professionals are more educated in treating the disease, they may be able to provide more useful information to patients rather than just turning them away. While hospital treatment is the ideal, educating sangomas and providing them with treatment resources could be a useful compromise. Though a diagnosis would have to be done at a clinic or hospital, allowing sangomas to distribute medication to already diagnosed patients would allow patients to use their preferred healer while simultaneously receiving the most effective care.

HIV co-infection

The TB epidemic is further complicated by the high comorbidity rate with other infectious diseases, particularly HIV. National data from 2006 stated that there is a 70% TB/HIV co-infection rate among all recorded TB patients.⁷ In Sub-Saharan Africa 40-60% of children treated for TB are HIV positive⁸ and over 50% of new TB cases in South Africa are in patients who are co-infected with HIV.⁷ In 2005, KwaZulu-Natal experienced over 25% prevalence of HIV in addition to more than 50,000 TB cases.⁷ Ayesha Kharsany, research associate at the University of KwaZulu-Natal, noted the corresponding trend of HIV and TB, stating, "As antenatal prevalence [of HIV] started rising...what we started seeing was a parallel increase in the caseload of tuberculosis as well."⁹ This co-infection likely occurs because immunosuppressed HIV victims more easily contract active tuberculosis than otherwise healthy individuals. This leads to a high HIV prevalence among all patients in TB clinics.⁹

At FOSA Hospital, the doctors estimate the TB/HIV co-infection rate among their patients to be 75-80%. Co-infection hinders treatment because it makes the healing process more complex and extensive. The FOSA Hospital has a policy that all patients be assessed at their HIV Counseling and Testing (HCT) Department. South African national policy says that any HIV-positive person is eligible to start lifelong antiretroviral (ARV) treatment if they have a CD4 count less than or equal to 350.¹⁰ However, should a patient test positive for TB, he/she will immediately begin treatment, regardless of their CD4 count. Because HIV attacks the immune system, the TB symptoms will not improve unless the HIV is addressed. Therefore, FOSA has made it a priority to test and counsel for HIV as a first step to treatment of TB. Frequent tests of CD4 count and Viral Load are conducted, and the results are recorded in the patient's file every week during doctors' rounds. These results tell the doctors the severity of HIV in the patient's body and therefore the level of disease that they face. The concurrency of HIV and TB is a noteworthy challenge that will need to be addressed in the coming years to reduce the burden of both diseases.

This concurrent epidemic is a particular problem among Zulu populations: due to the stigma associated with HIV, HIV patients may not be getting tested for HIV, or may not be open about their illness and treatment should they be diagnosed. While living in the Cato Manor Township in Durban, for example, I noticed there was a significant lack of communication regarding HIV. My Zulu friends and host family members were very willing to discuss health topics with me, with the exception of HIV. My fellow researchers noted a similar occurrence within their host families, which became a notable obstacle to completing health research surveys. The HIV stigma worsens not only the HIV epidemic, but also the TB epidemic indirectly. Improvement of this complicated relationship

between these two illnesses unfortunately relies heavily on social change, which is very difficult to enact. Organizations such as the Southern Africa HIV/AIDS Information Dissemination Service (SAfAIDS) have worked to understand and suggest solutions to the extensive HIV stigma in Southern Africa.¹¹ Some suggestions include educating religious leaders about HIV/AIDS and encouraging them to facilitate discussions in their services. I witnessed this when attending church with my host family, where the pastor spoke at length about HIV and had a patient share his story as well. Religion is a big part of the Zulu culture, so religious leaders are well respected. This makes them an effective outlet for HIV education and reducing stigma. Additionally, the media has been used to reduce stigma, particularly with health edutainment programs like *Soul City*.¹² This television soap opera series is popular amongst Zulu populations and displays HIV/AIDS information through popular characters, thereby raising awareness and reducing stigma. With continuing efforts like these, social change is possible, and the rippling effects can reduce the concurrent HIV-TB epidemics.

Side effects and patient response

Another major barrier to TB treatment as observed in Durban is the complexity of the treatment regimen, specifically with regard to treating side effects. National policy guidelines establish that "treatment spans must be determined based on individual culture date conversions, and must be a minimum of six months."⁴ This lengthy treatment requires numerous pills and frequent injections of a combination of various medications, which can be toxic and detrimental to the patient's body. There are a number of side effects that can occur as a result of the TB medications, ranging from diarrhea to psychosis. The majority of cases suffer from side effects no more severe than nausea and diarrhea, which can be treated with counter-effect drugs. However, aminoglycosides, used to treat MDR-TB, can cause hearing and vision problems, sometimes to the point of deafness and blindness. In addition, many of the hospital's HIV-positive patients also develop AIDS-related cancer, called Kaposi sarcoma. Epidemic, or "AIDS-defining," Kaposi sarcoma is a cancer of the cells around the lymph and/or blood vessels and presents itself as tumors on the skin or mucosal surfaces.¹³ The cancer can be crippling and requires chemotherapy treatment, which is not only taxing on the body, but further complicates treatment for FOSA patients; as FOSA does not have the necessary resources, they must be brought to a neighboring hospital for this treatment.

Some of the patients experience side effects so discomfoting that they stop taking their medications, choosing their vision or hearing over curing their TB. One Kenyan study of TB treatment defaulters showed 10.8% of observed cases reported not completing treatment due to side effects.¹⁴ A similar study done in Uganda reported a statistically significant correlation between side effects and defaulting from treatment.¹⁵ Though they can still transmit TB to the rest of their community, it is ultimately the patient's choice whether or not they want to suffer from these side effects. The treatment process for TB is inevitably complex, and the existence of side effects is an unfortunate reality that further complicates the process. Dealing with this phenomenon was a significant stressor observed amongst the doctors at FOSA, who were discouraged by their inability provide effective clinical treatment to patients due to the lack of adequate treatment of side effects and policies regarding patients who refuse treatment due to their side effects. This frustration places stress on the provider and, in turn, on the hospital and system as a whole.

Defaulting from treatment

Refusing TB treatment poses an immediate threat to medication compliance. Lack of adherence to treatment is a major problem because it leads to MDR and XDR strains of TB. The bacterium *Mycobacterium tuberculosis* that survived the previous treatment undergoes slow but constant and spontaneous mutations that give rise to increasingly drug-resistant organisms. The chance of spontaneous resistance to each first-line TB drug used in South Africa is about 1 in every 100 cell-divisions.⁴ With this rate of resistance across all first-line anti-TB drugs, the problem of

drug-resistance is extensive. Additionally, a 2002 survey showed that 6.7% of patients who had previously undergone treatment for TB were now undergoing treatment for MDR-TB.¹⁶ Interestingly, a 2010 study published in *The Lancet* showed that 72% of current XDR-TB patients in their cohort had previously been diagnosed and started on a treatment regimen for MDR-TB.¹⁷ This shows that a significant number of treatments of MDR-TB are also failing, as patient conditions are only getting worse. In early February, the Center for Disease Control and Prevention published a report that warned readers that the first cases of totally drug-resistant, and "virtually untreatable," TB were reported in South Africa.¹⁸ While it is unknown as to how long these strains of completely resistant TB bacteria have been in South Africa, nine cases discovered in one small area suggest that they have not developed recently.¹⁹ This is something that the healthcare system of South Africa will have to deal with in coming years.

A typical MDR-TB patient takes an average of six medications, while an XDR-TB patient takes eleven—without considering medications for countering side effects and HIV antiretroviral medications. The sheer number of medications makes it difficult and uncomfortable for patients to keep track of taking them all, especially when many are bitter or hard to swallow. It is particularly difficult for patients who must travel to clinics or hospitals for medication who are not being constantly monitored by health professionals because they take the medication at home. Treatment at home relies heavily on the patient's own active participation in the healing process, which makes it harder to ensure treatment than at an in-patient facility like FOSA. While staying in the rural area of Impendle, I spoke at length with my host family about the main difficulties of daily rural life. One of their main concerns included the lack of convenient transportation and access to health care facilities. For example, walking to town becomes dangerous when it rains, as people have to cross difficult terrain such as engorged rivers. This showed me that it would be difficult for a TB patient to access a clinic, and the difficulty of the trip may discourage patients from keeping up with their treatment.

Efforts such as Community Care Givers and tracer teams are used to help encourage medication compliance but have faced some problems in practice. In South Africa, there are many people employed as Community Care Givers (CCGs) who are not trained health professionals but rather are community members who have taken certain training courses that qualify them to distribute medication and make in-home visits to patients in their given neighborhood jurisdiction. These CCGs are key players in controlling TB outside of the hospital setting because they can visit TB patients and ensure they are taking their medications. However, it can still be difficult for CCGs to monitor patients at home because the patients are not always home when the CCG comes to check on them. When I was working with a CCG in the Newlands West Township, three out of four patients who we were trying to visit in one day were not home. This complicates the process of monitoring treatment regimens, as unmonitored patients and those defaulting from medication cannot be checked. Tracer teams, mobile units that travel to communities in order to track patients and assess whether or not they are receiving and taking their medication, play a similar role. While tracer teams are known to be effective, I was unable to find many teams that were doing this kind of work for TB patients. FOSA once had a tracer team that dissolved about six years ago, most likely due to a lack of funding. Thus, FOSA loses track of patients after they are released, and these patients may default from treatment without any health professional knowing.

FOSA Hospital also faces its own difficulties with keeping in-patients adhered to medication at times. Sometimes patients refuse treatment or run away from the facility because they want to return home. When this happens they are no longer under the medical supervision of the doctors and nurses, decreasing the likelihood of medication regimen adherence. Additionally, patients are sometimes granted pass outs for the weekend or holidays. During my time at FOSA, for example, many patients were going home for the Easter holiday. However, many patients did not return on time after the holiday pass out was over. There is nothing the staff can do to make these patients come back, and the longer they are

gone, the more likely they are to run out of medication or stop taking it. The doctors also informed me that many of the XDR-TB patients now in the facility previously had MDR-TB and refused treatment. They have now returned to the facility with a worsened case of XDR-TB because they did not stay on their treatments initially. Defaulting from treatment is a serious problem and allows the epidemic of XDR-TB to worsen.

Facilities like FOSA now have to try to combat very fatal forms of XDR-TB, which has proved to be a difficult task. The doctors at FOSA estimated that of 160 patients in the hospital, one third are XDR and only five to ten percent of those XDR patients will respond to treatment and recover. There is no policy in place for the 90-95% of patients who do not improve after nine months of treatment. One FOSA doctor phoned his superior in front of me to ask him what he should do with one of his patients who was failing treatment. As the doctor predicted, there was no answer. This policy gap is a problem because while doctors cannot tell patients that they must stay in the hospital away from their families at the end of their lives, it is a public health risk to send an XDR patient freely into the community. Though public health experts may argue that the patient must stay in the hospital, the lack of policy means it is up to the patient whether they want to stay or go home. While any patient who chooses to go home is still required to take medication at a local clinic, they are more likely to default from medication and spread the disease than if they were to remain in the facility. One FOSA doctor referred to this problem as a “revolving door” which is allowing XDR-TB to increase exponentially. There is no treatment for these patients and their release back into the community is allowing the rapid transmission and exponential growth of XDR-TB throughout South Africa.

In order to address the rising level of drug-resistant TB, the World Health Organization suggests starting with improved and more comprehensive surveillance data in order to gain a better understanding of the overall burden—not only in KwaZulu-Natal, South Africa, but also around the world. In 2012 there were 70 countries with continuous surveillance based on drug susceptibility testing (DST) of all diagnosed TB patients, and 66 countries based on testing of select representative samples.¹ With improved surveillance could come improved coverage of DST and improved understanding, which will allow for more focused and effective intervention. In response to the release of infectious XDR-TB patients back into their communities, a policy intervention would be the most plausible solution. Clinically, there is not yet a way to improve these patients, so a societal level intervention will be necessary. By creating a policy that restricts the release of infectious XDR-TB patients and limits their interactions with healthy individuals, we will be able to limit the rapid spread of XDR-TB after failed treatment. However, the prospect of such a policy forbidding the patients’ release is controversial because it could simply discourage patients from seeking treatment in the first place, for fear of being taken away from their families or communities. These conflicting views on policy intervention for failing patients will create interesting debates in the coming years in South Africa’s fight against TB.

Pediatric tuberculosis

Another emerging challenge in the South African TB epidemic is the increasing prevalence of pediatric TB. TB is generally considered a disease that affects adults, but recently its widespread infection of children has been more difficult to treat than TB in adults. Children comprise over 16% of all TB cases in South Africa, and Dr. Anneke Hesselning of Desmond Tutu TB Centre in South Africa even claims that with better detection we would find that 15-20% of cases worldwide are children.²⁰ Pediatric TB is a significant issue because children develop the disease more quickly and severely since they have less developed immune systems.²⁰ It is estimated that 70,000 children die each year from TB, a disease which is preventable and curable with effective prevention and treatment.²¹ Children frequently develop the most severe forms of TB, such as miliary TB, or TB with very small lesions but wide dissemination, and TB meningitis.⁸ This severity shows that an increased emphasis needs to be put on pediatric TB, not just TB in adults. “Young

children usually become infected after household exposure to an adult or adolescent with sputum smear-positive TB.”⁸ This could be prevented if the proper steps were taken to combat the disease and protect children. If health professionals ask TB patients if they have children in their home, it could help protect these children before they become infected.²⁰ For example, the doctors at FOSA recorded the number and ages of children whom each patient had so that they would be aware of potential infection should that patient be granted a weekend or holiday pass out. I also witnessed doctors speaking with any patient leaving the hospital campus about the potential they had to pass the disease to their families and children if they did not follow the doctors’ precautionary orders. Greater awareness from parents and health professionals like these could help significantly reduce the incidence of TB amongst children.

According to Hesselning, the problem of TB among children is worsening due to insufficient diagnostic efforts from the health care system. One problem is that children are often unable to produce sputum for testing; when they can, it is often a false negative because children often carry a lower, and therefore less detectable, level of TB bacteria.²¹ This is a major barrier to diagnosis and, subsequently, control of the disease. Additionally, children with diagnosed cases of TB do not receive proper treatment regimens. Since there is no recognized dose for children, children are given either adult dosages or approximated dosages with broken or crushed pills.²¹ Pediatric TB researcher Simon Schaaf admits that the proper dosage for children is actually unknown, and will remain so until funding for pediatric TB research is available.²¹ It is important to emphasize that TB can affect anyone of any age in any part of the world.

Based on my findings and the aforementioned challenges characteristic of the South African TB epidemic, there is much progress to be made in the fight against this epidemic. In the coming years health professionals need to take a number of steps in order to control the spread of disease and limit further effects of current epidemics. In sum, these steps include but are not limited to:

- Focus on primary prevention, with efforts such as health education that can raise awareness and prevent transmission altogether.
- Invest in TB research, and ensure that research efforts align with needs observed by health professionals on the ground.
- Coordinate with local and traditional healers to facilitate a wider health effort against infectious disease.
- Facilitate a parallel public health intervention that will concurrently address the HIV and TB epidemics.
- Invest in programs that will help reduce the number of patients defaulting from medication, perhaps by increasing community-level surveillance.
- Acknowledge the severity of and participate in research concerning pediatric TB.

Based on my experiences with drug-resistant tuberculosis amongst Zulu populations, I have seen that the KwaZulu-Natal province is facing a serious epidemic. The abovementioned challenges are barriers to successful healthcare and have created burdens for the Zulu population, health care professionals and the health care system alike. These challenges are by no means unique to South Africa; they can be seen in similar severity and spread in other populations worldwide as well. As we begin to unravel the epidemic’s challenges in one population, we can take lessons learned and apply them to combat these same challenges in other parts of the world. The Zulu population and their struggle with drug-resistant TB is just one example of how crippling communicable diseases can be on different populations around the world. The combat against infectious diseases will require a global effort based on the experiences and hardships of several populations, but with continued global progress we will be able to create a healthier planet.