

Community-Based Management of Multidrug Resistant Tuberculosis in Rural Kwazulu-Natal

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Abstract

Multidrug Resistant Tuberculosis (MDR-TB) is a significant health burden in South Africa, and it is particularly problematic in the region of KwaZulu-Natal. MDR-TB is not susceptible to most first-line medications, and anti-bacterial treatment for resistant bacteria may take up to 24 months to complete. The majority of this treatment process occurs outside the confines of the MDR-TB ward – in the community. This project examines the provision of community-based care to MDR-TB patients in a rural area of Northern KwaZulu-Natal, and attempts to understand the multifaceted system of MDR-TB control.

Community-based care is one of the essential steps in the treatment of MDR-TB due to the lengthy treatment process and the potential for adverse side effects. Without a comprehensive system of community-based care, MDR-TB has the opportunity to proliferate and to amplify its resistance. This project explores the roles, motivations, and skills of various community caregivers who are responsible for treating and overseeing MDR-TB patients in the community, such as the TB tracers, injection nurses, home assessors, and community health workers who all play integral roles in managing MDR-TB. Participant observation and informal conversations with these hospital personnel allowed for a comprehensive understanding of the management of MDR-TB in the community, and to assess the obstacles to care posed by a rural environment. This experience led to the conclusion that a comprehensive, community-based strategy is necessary for the containment of MDR-TB and that significant funding should be allocated for strengthening MDR-TB control systems.

Tuberculosis (TB), caused by the *Mycobacterium tuberculosis* bacilli, is a disease that dates back as far as 500,000 years [1]. TB is particularly problematic among poor and marginalized populations in resource-poor areas, and it remains endemic in many low-income countries in Africa, Asia, Europe, and South America. It is estimated that one third of the world's population (2 billion people) is infected with the bacillus, although the majority of these cases are latent or asymptomatic [2-4]. TB usually attacks the lungs but can affect other areas of the body as well, such as the spine, kidney, or brain. When people have an active infection cough, they propel TB bacilli into the air, spreading infection. South Africa has the third highest prevalence rate of TB in the world, lagging behind only China and India [5]. Tuberculosis is a major source of morbidity and mortality in South Africa, causing 5.5% of total deaths and posing

a significant hindrance to the development of the country [6].

Over the past several decades, a new threat has emerged: Multi-Drug Resistant Tuberculosis (MDR-TB), defined as any strain of TB resistant to the most efficacious first line drugs isoniazid (INH) and rifampin (RIF) [7]. Cases of MDR-TB are inordinately concentrated in resource-poor areas of Africa, Eastern Europe, Asia, and South America. Unfortunately, medical facilities in South Africa are not sufficient to treat the growing number of MDR-TB cases. In 2010, the amount of new MDR-TB cases in the province of KwaZulu-Natal exceeded the number of available beds in MDR wards by 352 [5].

While studying abroad for four months in South Africa, I had the opportunity to conduct a research project focused on the recent epidemic of drug resistant TB in KwaZulu-Natal, South Africa, a province that has the highest burden of drug resistant TB in the country. Treating MDR-TB is an 18-24 month process, and the majority of this process occurs outside of the hospital. I explored the various services that have been established to manage MDR-TB in the community and the workers who provided these services and analyzed the findings in a rural context to determine the difficulties associated with providing care. Drug resistant TB is a growing epidemic that shows no signs of receding. To address this epidemic and reduce MDR-TB globally, it is imperative that health systems invest in the support structures responsible for managing MDR-TB at the community level.

Methodology

This project was conducted over a 3-week period in the catchment [1] area of a rural hospital in northern KwaZulu-Natal, where a variety of community-based activities that contribute to the surveillance, control, and treatment of MDR-TB were observed. Primarily, qualitative data was gathered through numerous informal conversations with health professionals. This was supplemented with a variety of secondary sources from academic journals and websites. The hospital and all hospital personnel will remain anonymous throughout this paper to protect their integrity and privacy. The hospital will be referred to as Hospital X. Hospital X is a 280-bed district hospital, belonging to the KwaZulu-Natal Department of Health. It serves a predominantly Zulu population, with some patients crossing the border from Mozambique to receive care.

Results and Discussion

Home Injections

An effective treatment regimen for a patient that presents with MDR-TB typically lasts between 18 and 24 months, and

this necessitates the provision of injections directly to the home [8]. Those who test positive for MDR-TB are hospitalized in the MDR-TB ward and immediately started on injection therapy with either amikacin (AMK) or kanamycin (KM). This injection is administered to the patient six days a week for approximately two months in the hospital ward. Each month, patients must provide a sputum sample to test for the presence of bacilli. Typically the patient's sputum (mucus from the lower airways) will convert to negative after a period of two months on injections (Nurse 1, Personal Communication, November 8, 2011). According to Department of Health policy, "patients who have negative sputum microscopy and who are clinically not too ill may be initiated on MDR-TB treatment as outpatients if access to daily injections can be organised." [2]

MDR-TB patients should be visited at home by a mobile team five days a week for the duration of the injectable phase of treatment. During visits, the team will administer injectable drugs, monitor side effects, provide health education, and assess household infection control practices [2]. This constant maintenance is essential, because the interruption of injection treatment may amplify the already resistant bacilli, leading to extensively resistant bacteria.

Hospital X has implemented a community-based program to ensure that all MDR-TB patients adhere to the 6-month injection regimen even after discharge from the hospital ward. One nurse from the HAST (HIV, AIDS, and Sexually Transmitted disease) ward has the sole responsibility of driving to the homes of MDR-TB patients and administering injections. It is impractical to assume that the patients or their family members are capable of providing injections due to the difficulty of such a procedure. It is also unrealistic to keep MDR-TB patients in the ward for the duration of the 6-month injection treatment, as resident patients must be discharged to make room for new ones. Therefore, community-based injection treatment is an essential aspect of a successful MDR-TB treatment program.

It is also important to consider the impact of injection treatment on children infected with MDR-TB. Six months of injections place a heavy burden on both the child who must endure the painful procedure and the healthcare professional who must administer the treatment. As one nurse stated, "Another challenge is treating the children with injections. Children normally cry when you give them immunizations, so imagine giving injections for six months? It's not easy to be their enemy" (Nurse 1, Personal Communication, November 8, 2011). In some situations, the injection nurse may be forced to administer treatment while the child is at school, which may reinforce the stigma surrounding TB and exacerbate the emotional strain for the child. The injection nurse at the hospital commented on this scenario: "Sometimes I must give injections at school and when the other children see them [the patients] getting the injections they will make fun of them [the patients] and isolate them because they think they [the patients] are sick" (Nurse 1, Personal Communication, November 8, 2011). Therefore, community support structures must be established for children who are subjected to treatment for MDR. It is also essential that the patients' peers are educated about the condition so misconceptions are not perpetuated and children are not ostracized as a result of their condition.

Linking Patients with a DOT Supporter

DOTS (directly observed therapy short-course) has been the cornerstone of TB treatment regimens since it was established in the 1980s by a doctor in Tanzania, and successful treatment outcomes are predicated from the implementation of an effective DOTS program [7]. DOTS is a comprehensive program that relies on government support, a steady supply of antituberculosis drugs, a successful monitoring system, and diagnostic capabilities. The central tenet of DOTS is that all doses are taken under the direct supervision of another individual (a DOT supporter), in order to ensure patient compliance [4].

Directly observed treatment takes on a greater significance in the context of MDR-TB due to the duration of treatment and the complications associated with treating drug resistant strains. The 24-month treatment regimen increases the probability of interruption or default in comparison to the six month, short-course regimen (Nurse 3, Personal Communication, November 14, 2011). In addition, adverse reactions to treatment are increasingly likely with second line drugs. Many countries have adopted a DOTS-Plus program to combat MDR-TB, which is more complex than the traditional DOTS strategy.

The nurses at Hospital X must ensure that every MDR-TB patient is linked with a DOT supporter as soon as they are discharged from the hospital. The DOT supporters will supervise the ingestion of treatment in the community and monitor any adverse effects that develop. DOT supporters must watch the patients take their medication and record that they have done so on a card that is turned in at the monthly clinic appointments. At Hospital X, there is no specific DOT protocol but it is the responsibility of hospital personnel to link patients with a DOT supporter in the community (Nurse 3, Personal Communication, November 14, 2011). In the majority of situations, the DOT supporter is a family member, but community health workers, neighbors, or home-based caregivers may also serve this role. When the patient is first registered in the MDR-TB ward at the commencement of treatment, he is required to provide the name of someone who will serve as the DOT supporter for the duration of his treatment in the community (Nurse 2, Personal Communication, November 14, 2011). For example, one patient who was to be discharged from the MDR-TB ward lived with two sons, both of whom were teenagers. While conducting the home assessment, the nurse was concerned that the older son would not be a suitable DOT supporter due to his age and demeanor. However, the nurse located a nearby family member who was willing to supervise the patient during the treatment regimen. The nurse deemed this woman better suited to the responsibility of a DOT supporter in this situation, and he proceeded to educate her about her role in the patient's treatment regimen. The nurse discussed the duration of the treatment and the importance of patient compliance. Due to the remote location of many homes and the lack of health facilities in rural settings, family members are usually the only option for DOT support. As one tracer stated "there is no other way around" (TB Assistant, Personal Communication, November 3, 2011). However, according to Department of Health policy, "Family members should be used only as a last option [for DOT] because they may be coerced by other family members, making them less objective as community caregivers." [2]

It is essential that hospital personnel develop a system for

linking MDR-TB patients with DOT supporters if the patient lives alone or does not have an adequate support system at home. In this situation, home-based caregivers may be the only option for DOT support. Occasionally, community health workers may act as a DOT supporter, but this is rare due to their heavy patient burden. "It is difficult for us to provide DOT," lamented one community health worker. "The patient must be observed every day and we have too many patients to see so it [the DOT supporter] is usually a family member." (Community Health Worker 1, Personal Communication, November 9, 2011)

Therefore, it may be necessary to employ home-based caregivers in the provision of directly observed treatment in the community. A community health center, located just outside the Hospital X gates, is an NGO that trains home based caregivers in the provision of DOT. These caregivers differ from community health workers in that their services are completely voluntary. The NGO employs 130 such community volunteers who reach into 45 of the 48 tribal areas in the Hospital X catchment area (NGO Personnel, Personal Communication, November 15, 2011). If MDR-TB patients cannot locate a DOT supporter to supervise their treatment regimen, the NGO is able to provide this service for the duration of the treatment regimen (Nurse 1, Personal Communication, November 8, 2011). It is evident that the successful treatment and surveillance of MDR-TB in the community is heavily reliant on community caregivers; the impact of these non-professional health workers in maintaining patient compliance cannot be understated.

Preventing Interruption and Default: TB Tracers

The interruption and default of treatment among MDR-TB patients is usually caused by the lengthy and grueling treatment regimen associated with the condition. 'Interruption' is defined as a failure to take treatment for two months or less, while 'default' is a failure to take treatment for over two months (TB Assistant, Personal Communication, November 3, 2011). The factors that lead to default among TB and MDR-TB patients are poorly understood but often include personal stresses, such as alcoholism, pessimism, previous negative experiences with TB treatment, health care service limitations, and the need to earn money [9].

One of the most apparent reasons for the interruption of MDR-TB medication is the potential appearance of side effects (Nurse 3, Personal Communication, November 14, 2011). All TB drugs have been reported to cause adverse reactions and one of the most common side effects is progressive hearing loss [10]. Other common side effects range from mild (dizziness, headaches, fatigue, nausea, diarrhea, anxiety, etc.) to severe (depression, seizure, peripheral neuropathy, psychosis, suicidal ideation, etc) [10]. According to the audiologist at Hospital X, approximately nine out of ten MDR-TB patients experience some level of hearing loss (Hospital Audiologist, Personal Communication, November 8, 2011). Another common reason for default is that patients start to feel better before the treatment is complete. According to the injection nurse at Hospital X, many patients stop their treatment prematurely when their symptoms are alleviated. "When we ask the reason [for defaulting] it was that the patient was feeling well. They decided to stop treatment because they are no longer coughing, they are no longer sweating at night, they think they are fine" (Nurse 1, Personal Communication, November 8, 2011).

However, patients are not fully recovered at this point and must follow through with their drug regimen to ensure a positive treatment outcome. Another nurse echoed these sentiments, attributing this behavior to a lack of proper patient education.

I think the people don't understand why they have to be treated for so long when immediately they convert. With TB, one becomes very sick, very quickly, and then immediately they commence the treatment they feel much better and then they stop, and 3 or 4 months down the line they are completely better but they have to continue with the treatment. If they're not properly health-educated they will default with the treatment (Nurse 2, Personal Communication, November 14, 2011).

According to Department of Health policy, one key element for a successful MDR-TB program is the establishment of "functional defaulter tracing teams that conduct home visits, identify contacts and trace defaulters." [2] The tracing team at Hospital X are nurses associated with the HAST unit. Following discharge from the MDR-TB ward, patients must travel to a hospital or clinic for a monthly review, which includes a sputum test, determination of weight and vital signs, monitoring of side effects, and collection of treatment (which is provided in tablet form) (Nurse 2, Personal Communication, November 14, 2011). When patients fail to appear for their monthly appointments, tracer teams are sent into the community to locate them and bring them to the hospital. In addition, if the monthly sputum test shows that a patient has converted from negative to positive, the tracers are immediately sent into the community to locate the patient and inform him to return to the hospital. Efficient and well-organized tracing can prevent the transmission of bacilli among family members of infected patients. In certain situations, if the tracer believes a patient's condition is too severe for home-based care, he may determine that the patient requires further hospitalization and return him to the ward, despite the fact that he has been discharged by a physician (TB Assistant, Personal Communication, November 3, 2011). This prevents further transmission between those in the patient's household.

Tracers may also be utilized to locate patients who have interrupted their injection treatment. Although it is rare, patients who are still on injections may interrupt their drug regimen for various reasons. For example, some patients experience noticeable pain during injections. One man was not present for his injection, and the nurse attributed this to his reluctance to endure the pain (Nurse 1, Personal Communication, November 8, 2011). As a result of the pain associated with the treatment, some patients will flee their home when they see the hospital personnel arriving to administer injections. In this case, tracers will be sent to find them and encourage them to adhere to the treatment.

Home Assessments

After the conversion of sputum to negative, MDR-TB patients will be released from the hospital ward to return to their homes. It is imperative that health workers facilitate the transition from hospital to home for MDR-TB patients. If a high quality of home life is not maintained, there could be deleterious results for the patient and the patient's family. In order to make certain that MDR-TB patients are being released to a home environment

that is conducive to their medical situation, TB tracers, nurses, or community health workers will conduct a home assessment. Department of Health policy dictates that home assessments include the following:

Ensuring adequate ventilation/open windows, isolating patient (own bedroom where possible), promoting cough hygiene, ensuring that patients use surgical mask during waking hours while at home or when meeting with others; refraining from close contact with children; maximising time in open-air environment (e.g., receiving visitors outside) [5].

The first consideration is often the patient's sleeping situation: the patient must be isolated during the night to prevent further transmission of bacilli to family members. It is also essential that the patient sleeps alone and that the sleeping room is well-ventilated (Figure 1 for an example of a poorly-ventilated house). This may prove difficult if the patient lives in an overcrowded home. According to the TB tracer, "there may be a family of 9 living in one room and when they are sleeping they are all breathing the same oxygen" increasing the probability that the infection will spread. If the patient cannot be isolated during the night, the health worker must find other sleeping arrangements with a neighbor, family member, etc. (TB Assistant, Personal Communication, November 3, 2011). If alternative arrangements cannot be coordinated, the patient's discharge from the MDR-TB ward will be delayed.

The assessment also serves as an opportunity for the health personnel to educate family members about the complexity of the MDR-TB treatment process. It is important that both family members and patients thoroughly understand the importance of adhering to treatment and the potential consequences if treatment is interrupted. As one nurse stated, "One of the most difficult things about MDR is properly educating the patient and making him understand the severity of the condition" (Nurse 1, Personal Communication, November 8, 2011). If patients and families are properly educated, the probability of patient noncompliance is decreased and family members gain the knowledge they need to protect themselves. When I observed the education of a family during one home assessment, the tracer surveyed the family about their knowledge of MDR-TB, including symptoms and modes of transmission. He also emphasized the importance of adhering to the treatment, and described the potential consequences of patient noncompliance. Another aspect of the home assessment is determining the patient's proximity to a nearby clinic, which is essential in a rural environment like the Hospital X catchment area, where MDR-TB patients may live significant distances from the hospital. As a result of the isolated and distant location of many patients, the hospital injections nurse may be unable to reach all patients to administer injection treatments. Therefore, the home assessor must determine the closest clinic or hospital where the patient can receive injections.

Finally, the home assessor must ensure that the patient has a stable living situation, with some level of familial support, and a form of income. As one tracer stated, "The patient may have his own room, but is there anyone looking after him, is there any DOT supporter?" (Nurse 1, Personal Communication, November 8, 2011). If the patient's living situation is not conducive to his continued improvement and overall wellbeing, interventions



Fig. 1. An example of a rural road in the Hospital X catchment area. (Photo taken by author)

from social workers may be necessary. For example, the social worker may take measures to ensure that adequate food is available, as many patients in resource-poor areas may not have any means to generate an income and to maintain a balanced diet (Nurse 3, Personal Communication November 14, 2011). If the home assessor determines that patients cannot maintain an adequate standard of living they may choose to consult a social worker, who can travel to the home of the patient and conduct his own assessment to determine the appropriate course of action. If necessary, the patient may receive government nutritional assistance. The federal government has established grant programs to provide food to those who cannot afford a sufficient diet. In addition, many MDR-TB patients may qualify for federal grants to supplement their income and aid in their continued recovery (TB Assistant, Personal Communication, November 3, 2011).

Difficulties of Providing Care in a Rural Area

A rural environment poses many significant obstacles to the provision of quality healthcare to MDR-TB patients. In the Hospital X catchment area, homes are dispersed over a wide geographic area, and many people reside a significant distance from any type of medical facility or clinic. This is problematic during the months following discharge from the MDR-TB ward, when a health worker must travel to the home of the patient to administer injection treatment. For a four month period, MDR-TB patients must receive injectable second line drugs while they are living in the community, but if patients do not live in close proximity to the hospital, it may be necessary to travel to a nearby clinic to receive injections. The hospital has established relationships with local clinics in order to link MDR-TB patients with these healthcare facilities. However, in certain situations, even clinics are not able to provide MDR-TB patients with the care that they require. It is evident that some patients simply reside too far from an established medical facility or a qualified

medical professional who is capable of administering injections. As a result, they are not able to receive their required four-month regimen of injections (Nurse 1, Personal Communication, November 8, 2011).

In some instances, MDR-TB personnel may find themselves in the rare situation where it is simply infeasible to provide injections in the community. In this case, it may be necessary for the patient to remain in the MDR-TB ward for six months or the duration of the injection treatment course. This is highly discouraged due to the limited space in the MDR-TB ward and this option should only be pursued if absolutely necessary (Nurse 3, Personal Communication, November 14, 2011). I observed this phenomenon during one home assessment in a village approximately one hour from the hospital. In a village located approximately one hour from the hospital, it was unrealistic to expect an injection nurse to deliver injections directly to this patient due to the sheer distance. However, the patient's home was located several kilometers from the nearest clinic, a location that was simply not walkable. According to the patient, travelling to the clinic six times a week for four months to receive injections would be a R 1200 (USD 135) expenditure, a cost that was unaffordable (TB Assistant, Personal Communication, November 3, 2011). The home assessor did not have a solution to the situation and he stated that the only option was to keep the patient in the MDR-TB ward for a six-month period (TB Assistant, Personal Communication, November 3, 2011). Scenarios like this demonstrate that it is necessary to weigh the probability of patient default against the personal and economic burden associated with six months of isolation in the MDR-TB ward.

The impact of the rural environment on MDR-TB management was very apparent in other ways. As mentioned, homes are dispersed over a wide geographic area with no sense of organization. Many of the homes are makeshift or informal huts with no address (See figure 1). As such, it is imperative that those involved in the treatment and surveillance of MDR-TB in the community are familiar with the area and can locate the many homes found only by driving down unmarked dirt roads through dense bush and shrubbery (See). Various landmarks like trees and rivers were the only means of distinguishing specific locations. Therefore, familiarity with the terrain is a must for health workers in rural areas. Another obstacle posed by the rural setting lies in linking patients with DOT supporters. Ideally, all MDR-TB patients would be linked with a community health worker, nurse, or other medical personnel for the provision of directly observed treatment. Because healthcare workers are familiar with the severity of MDR-TB and the importance of compliance to treatment, they are very effective as DOT supporters [4]. However, due to the remote location of many rural homes and the lack of healthcare facilities in such an environment, it is simply impossible to link all patients with a healthcare worker for DOT support (Nurse 2, Personal Communication, November 14, 2011). Therefore, family members have emerged as the only option for directly observed treatment. Based on these observations, it is imperative that the impact of a rural environment is considered when implementing community-based programs for MDR-TB control. Otherwise, the obstacles and limitations posed by a rural setting could have disastrous effects for MDR-TB healthcare personnel.



Fig. 2. An example of a rural road in the Hospital X catchment area. (Photo taken by author)

Conclusion

MDR-TB is a complex problem placing a significant financial burden on an already struggling healthcare system. In KwaZulu-Natal, MDR-TB has emerged as one of the most critical health concerns, and the incidence of new MDR-TB cases over the last several years is greater than that of any other South African province [2]. There is a great need for medical facilities and personnel for the treatment and surveillance of MDR-TB patients, as many MDR-TB treatment centers remain overcrowded, understaffed, and simply unable to care for all infectious disease patients. Therefore, community support structures must be in place to maintain patient adherence to therapy during the long and arduous treatment regimen. If the management of MDR-TB in the community is not a priority, patient noncompliance may result in the development of extensively resistant strains of TB.

This project allowed for a comprehensive understanding of MDR-TB control in one rural community. Although some observations may not generalize to all communities dealing with MDR-TB, they can certainly be applied in a variety of settings. All health personnel consulted for this project -- nurses, TB tracers, doctors, and other health workers -- are essential in developing a community-based program for managing MDR-TB. These individuals are interconnected in a complex system of treatment and control, and their importance cannot be understated. It is important that South Africa and other nations with a significant MDR-TB burden invest in the training of these personnel in order to manage this growing epidemic and prevent further morbidity and mortality. Experiences with these individuals have reinforced the point that MDR-TB patients cannot be neglected when they leave the hospital. Health personnel must take the proper measures to ensure that patients receive sufficient care during the duration of their treatment including education, symptom management, DOT support, etc. Government health authorities must prioritize MDR-TB diagnosis and treatment and allocate sufficient resources to ensure that this epidemic is contained. The successful management of MDR-TB at the community level is imperative in the global fight against TB and it cannot be neglected, especially in resource-poor countries where the burden is greatest.

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