There is growing interest in the geographies of health and a continued interest in what has more traditionally been labeled medical geography. The traditional focus of 'medical geography' on areas such as disease ecology, health service provision and disease mapping (all of which continue to reflect a mainly quantitative approach to inquiry) has evolved to a focus on a broader, theoretically informed epistemology of health geographies in an expanded international reach. As a result, we now find this subdiscipline characterized by a strongly theoretically-informed research agenda, embracing a range of methods (quantitative; qualitative; and the integration of the two) of inquiry concerned with questions of: risk; representation and meaning; inequality and power; culture and difference, among others. Health mapping and modeling has simultaneously been strengthened by the technical advances made in multilevel modeling, advanced spatial analytic methods and GIS, while further engaging in questions related to health inequalities, population health and environmental degradation.

This series publishes superior quality research monographs and edited collections representing contemporary applications in the field: this encompasses original research as well as advances in methods, techniques and theories. The Geographies of Health series will capture the interest of a broad body of scholars, within the social sciences, the health sciences and beyond.
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Chapter 14
Tuberculosis: A Scourge for Development?

Jana Fried and John Eyles

Introduction

In this chapter, we will examine the case of tuberculosis (TB), focusing on the TB epidemics current global spread, its drivers and health sector responses. Along with the epidemiological transition in many richer parts of the world, TB had moved out of the general public’s awareness and become a ‘forgotten plague’ (Farmer 2001; Barnes 1995). Attention only recently renewed somewhat with the increasing co-occurrence of HIV and TB and media headlines on drug-resistant TB (e.g., Boseley 2011; Tackling TB better 2011). However, in her book on the public perception of TB in the United States, Ott (1996) notes that TB is not actually an emerging or re-emerging disease and that such labelling obscures its persistently high global prevalence levels over decades. In the decades since the 1980s, there has been a threefold increase in reported cases to 2005 but some decline since then (WHO 2011; 2012b). Benatar and Upshur (2010) argue that TB has passed through four eras, the first two seeing the disease and its successful treatment in Europe and North America. The third phase may be regarded as a time of denial and social failure, marked by the development of drug-resistant strains—a dimension already recognised as a possibility when the therapies were initially started. In fact, in 2009 and 2012, the globally first two clusters of totally drug-resistant TB cases were reported in Iran and India, respectively (Velayati et al. 2009; Ududiani et al. 2012). In 2011, 8.7 million people newly developed active TB and 1.4 million died of the disease. Why should this be the case as TB, like several other infectious diseases, is both preventable and curable (see WHO 2012b)?

In fact, TB reduction is one of the three infectious disease-related Millennium Development Goals (MDG 6) (together with HIV/AIDS and malaria) that aim to decrease disease burden and mortality rates. It is also one of the goals of the Global Fund to Fight AIDS, TB and Malaria (The Global Fund 2012). Some progress toward these goals has been made, however, it is challenged by the resource-limited environments of many developing countries and in those experiencing abrupt economic and political change.

In this chapter, we argue that TB remains problematic largely because of societal failure, stemming from the ways in which human societies are structured and operate with massive inequities in resources among and between social groups. As Farmer (2001) puts it, the forgotten plague was forgotten largely because it had stopped bothering the wealthy. In fact, the British playwright Arnold Wesker asked ‘Whatever happened to the good old days: you know, dirty attics, tuberculosis and general all-round suffering?’ With improved living conditions and available medical interventions, it seemed a problem of the past.
Yet nearly 20 years ago, Porter and McAdam (1994, 303) reaffirmed that ‘tuberculosis is a disease of poverty ... it spreads readily in crowded conditions and among the malnourished’. Thus, TB in today’s developing countries is similar to the situation in Europe and North America in the 1930s, exacerbated by frequent co-infection with HIV. It is telling that Farmer (2001) regards TB as ‘the consumption of the poor’. This economic link between TB incidence and poverty has been identified in many studies (see WHO 2005; Harling et al. 2008; De Alencar Ximenes et al. 2009) and reviewed by Dye et al. (2006) and Lonroth et al. (2010). The demonstration of an economic gradient and the area effects of deprivation add pessimism to attempts to control TB. Rasathan et al. (2011) point to intermediate risk factors which may worsen the risk to succumb to TB among the disadvantaged, such as crowding and thus heightened exposure to those already infected, poorly ventilated dwellings with indoor burning of biomass, and increased vulnerability due to poor nutrition and to HIV infection. All these factors indicate a close link between TB epidemiology and development, as both the spread of TB impacts (economic) development and vice versa. Thus it is important to note that – due to TB’s dynamic relationship with productive capacity (see Delfino and Simmons 2005) – the illness has a draining effect on economies with an estimated 0.2 to 0.4 lower growth for every 10 per cent higher incidence of TB (Grimmard and Harling 2004). We will examine these individual and societal impacts globally and then at different geographical scales in the contexts of the former Soviet Union and South Africa.

Why is Tuberculosis Important?

Tuberculosis is a contagious disease, spread through the air. It is caused by the bacteria Mycobacterium tuberculosis that predominantly affects the lungs of a person (pulmonary tuberculosis). While an estimated third of the global population are carriers of the bacteria, only people having active TB, i.e. those that are sick with TB in their lungs, are infectious (WHO 2012a). TB’s importance is partly determined by its scale and the ease of its transmission as 5–10 per cent of people who are infected with TB bacilli (but who are not infected with HIV) become sick or infectious at some time during their life. People with HIV and TB infection are much more likely to develop active TB. Left untreated, a person with active TB disease will infect on average between 10 and 15 people every year. People infected with TB bacilli will not necessarily become sick with the disease but it becomes a killer when immune systems are compromised. It is a disease of poverty affecting mostly young adults in their most productive years (WHO 2012a; 2012b).

The vast majority of TB deaths are in the developing world. The 22 countries with the highest disease burden carry more than 80 per cent of the global TB disease load (WHO 2012b). As mentioned above, nearly one and half million people died annually from TB in both 2010 and 2011 (WHO 2011, 2012). But the TB death rate has fallen by 41 per cent since 1990, and the absolute number of deaths is also declining. In addition, the global incidence of TB has started to decrease since 2001, reaching a decline of 2.2 per cent between 2010 and 2012. This is a promising indication of achieving some of MDG 6 sub-targets. Yet there were 8.7 million new TB cases in 2011, of which 2.9 million were women and 1.1 million were co-infected with HIV (WHO 2012). In order to understand these numbers, it is important that it is not just the poverty of individuals but the resource limitations of many countries that remain problematic.

Drug therapies are available and are helping to save numerous lives, but resistance can occur when therapies are missed or mismanaged. Examples include patients that do not complete their full course of treatment; health-care providers who prescribe the wrong treatment, the wrong dose, or length of time for taking the drugs; drug supplies that get interrupted; or drugs that are of poor quality (CDC 2011). All these have contributed to the development of multidrug-resistant (MDR)-TB, currently still underlined by the fact that MDR most commonly develops in the course of TB treatment. Multidrug-resistance describes a situation where a mycobacterium is unresponsive to at least the two most effective first line drugs (WHO 2012a). Such outbreaks occur more readily in people with weakened immune systems (e.g., patients with HIV). Outbreaks among not immune-compromised, healthy people do occur, but are less common. Complicating things further is the rise in extensively drug-resistant TB (XDR-TB), strains that are resistant to isoniazid and rifampicin, and resistant to at least one of three injectable second-line drugs (i.e., amikacin, kanamycin, or capreomycin) as well.

Remaining treatment options are few and, as underlined by the above mentioned first clusters of totally drug-resistant TB, are increasingly under threat. WHO estimates that there were 310,000 MDR-TB cases in 2011, up from 65,000 estimated cases in 2010 (WHO 2011; 2012b). In 2010, the largest WHO MDR-TB survey reported the highest rates of MDR-TB thus far, with peaks of up to 28 per cent of new TB cases in parts of the former Soviet Union (WHO 2011). XDR-TB has been found in 84 countries in 2011. This development is particularly problematic considering that XDR-TB has an extraordinarily high mortality rate. A study in a single case area in Kwazulu-Natal (South Africa) showed that from 2005 to 2007, 272 MDR TB and 382 XDR TB cases were diagnosed with HIV co-infection rates of 90 and 98 per cent, respectively. One-year mortality was 71 per cent for patients with MDR-TB and 82 per cent for those with XDR-TB. Fortyeight per cent of MDR TB and 51 per cent of XDR TB patients died within 30 days of the first diagnosis attempt (spitum collection). Hence, one-year and 30-day mortality rates were worse with increased drug resistance (Gandhi et al. 2010). One-year mortality among both MDR and XDR TB patients improved from 2005 to 2007, but the majority of deaths still occurred within the first 30 days. The lack of treatment success is not only lamentable for the individual lives lost, it also raises the dread of a transmitted (rather than treatment-acquired) multi-drug-resistant strain.

In order to address some of the challenges around lack of treatment-adherence, treatment-success and development of drug-resistencies, WHO has been recommending the adoption of the Directly Observed Therapy, short-course (DOTS) since 1995. This control strategy involves five key components, including political and financial commitment; early case detection and diagnosis; standardised treatment with patient supervision and support; effective drug supply systems; and adequate monitoring and performance management (WHO 2012b). Since its introduction, WHO (2012a) estimates that more than ‘51 million people have been successfully treated and an estimated 20 million lives saved through use of DOTS and the Stop TB Strategy’. Nonetheless, TB remains to present challenges to medical science but also to public health, civil rights and economic development. These challenges will emerge in the following sections.
Tuberculosis: The Global Picture

In 2011, the estimated per capita TB incidence rates were falling in all six WHO regions. Between 2010 and 2011, the decline in incidence rates per capita was for the first time big enough to offset population growth, hence the absolute number of new cases arising each year was finally falling, although slowly (WHO 2012b). WHO (2012b) estimates that the largest burden of TB disease in 2012 occurred in the South-East Asia and Western Pacific Regions, with India and China alone accounting for 40 per cent of global prevalence cases. However, the African Region carries 24 per cent of the global TB disease burden and has the highest prevalence and mortality rates. Globally, the highest number of deaths was in the Africa Region. Crucially, in terms of future productive capacity, 10 million children have been orphaned because of parental deaths from TB. Many of these cases are now associated with HIV.

Tuberculosis: A Regional Picture

Economic Decline and MDR-TB

We now examine the regional scale. The countries of the former Soviet Union are facing a serious and widespread epidemic with the highest prevalence of MDR-tuberculosis ever reported. Almost half of all TB cases in countries of the former Soviet Union are resistant to at least one drug in one in eight new cases. As well, one in three retreatment cases are MDR (WHO 2011). In this region, MDR-tuberculosis cases have more extensive resistance patterns and the highest prevalence of XDR tuberculosis (WHO 2011). Trend data from the Baltic countries probably represent the best situation within this region, with the prevalence of MDR tuberculosis in new cases remaining stable and tuberculosis notification rates declining. This may be an indication of political commitment and long-term investment in tuberculosis control, optimum management of susceptible and drug-resistant tuberculosis cases, and an improving socioeconomic situation. By contrast, the data reported from two Russian oblasts with well-performing tuberculosis control programmes (implementing the WHO recommended strategy to control TB and with decreasing tuberculosis notification rates) show increases in both absolute number and prevalence of MDR tuberculosis in new cases and a slowly declining tuberculosis notification rate (Wright et al. 2009). The increasing rate of MDR-TB in this region is related to TB's common associations—poverty, crowding and ineffective treatment, including environmental, structural, and operational factors that place adherence to treatment beyond a patient's control. The existence of selective environmental pressures on M. tuberculosis that cause it to acquire drug resistance—thought to be the result of patients receiving wrong prescriptions or taking anti-TB medications irregularly—are directly linked to broader social, economic, and political determinants that affect a patient's access to appropriate medications and appropriate care.

TB thus increased in Eastern European countries because of economic decline and the general failure of TB control and other health services since 1991 (Shilova and Dye 2001). Drug resistance is likely not the primary cause but a by-product of the events that led to TB resurgence in these countries. First, resistance is generated initially by inadequate treatment caused, for example, by interruption of the treatment schedule or use of low-quality drugs. Second, resistance levels tend to build up over many years, and yet TB incidence increased suddenly in Eastern European countries after 1991. Third, although formal calculations have not been done, resistance rates are probably too low to attribute all of the increase in caseload to excess transmission from treatment failures (Dye and Floyd 2006). Russia is not a poor country but the social and economic upheaval after the collapse of the Soviet Union resulted in profound wealth disparity and greater poverty among already marginalised populations. The abrupt economic and political transformation in the 1990s was associated with increases in alcohol consumption, a breakdown of health and social services, and socioeconomic instability. Differences in mortality by socioeconomic status (e.g. income, educational level, and type of employment) widened in the 1990s, especially among alcohol-related deaths and those due to infectious causes. As social cohesion became increasingly fragmented in Russian society, individuals living in relative poverty became further isolated and unable to access formal and informal resources, including health services and social support. It is in this context that the Russian Federation witnessed a reversal of 30 years of TB control. Between 1991 and 2001, TB incidence rates in Russia increased from 34 to 88 per 100,000, and TB mortality climbed from 8.1 to 19.9 per 100,000. In the region of Orel, near Moscow, risk factors for mortality were unemployment and homelessness, highlighting the role of poverty in poor TB outcomes. A drastic rise in petty crimes created ideal conditions for generating a TB epidemic. Overcrowded prisons and pre-trial detention centres were crammed with individuals from the poorest sections of society, the alcoholic, homeless, and mentally ill. TB incidence rates in Russian prisons were as high as 7,000 per 100,000. In the 1990s, prisoners made up approximately 25 per cent of all newly diagnosed TB cases in Russia and approximately 30 per cent of newly diagnosed civilian cases had a history of prior imprisonment. Although the prison system may have functioned as an 'epidemiological pump', releasing tens of thousands of active TB cases into the civilian population, the same forces driving the prison epidemic were independently contributing to rising rates of TB in the civilian population (Keshavjee et al. 2008, Stuckler et al. 2008). Tuberculosis remains a serious threat to public health in Russia and other former Soviet Union countries. Marx et al. (2009) examine this issue in terms of the characteristics of the
traditional Russian TB control model inherited from the Soviet Union. They further note that in 2006, nearly 125,000 TB cases and 28,000 TB deaths were notified in the Russian Federation. The TB notification rate was 13 times higher than in Germany. Thus while there has been some improvement, economic marginalisation, high rates of imprisonment, and infrastructural and treatment problems have created a perfect storm for MDR-TB and potentially XDR-TB.

**Tuberculosis: A Local Picture**

**TB and HIV in South Africa – Experiencing the Disease and the Loss of Civil Rights**

We now turn to South Africa and a national and localised picture in Africa that is facing the worst tuberculosis epidemic since the advent of the antibiotic era (Chaisson and Martinson 2008, 1089). On this continent especially, the epidemic has been exacerbated by the presence of HIV infections which have also worsened life circumstances. This is particularly true for South Africa that remains the only high burden country (out of 22) where TB incidence is still increasing (WHO 2011). Local studies, such as that by Kritzinger et al. (2009) in Cape Town, indicate that any progress in reducing the population burden of TB, with highest rates of increase found in the provinces KwaZulu-Natal and Eastern Cape.

The distribution of tuberculosis is associated with factors similar to those found in Russia. A low level of personal education, unemployment and a low level of household wealth were associated with increased odds of tuberculosis. Individuals living in areas of high inequality had an increased prevalence of tuberculosis disease, independent of their individual- and household-level risk factors. Alcohol abuse, cigarette smoking and low Body Mass Index (a proxy for poor or insufficient food intake) were independently risk factors for tuberculosis in South Africa, even after adjusting for the SES of individuals. A recent meta-analysis found the relationship between smoking and tuberculosis to be statistically significant, and stronger in those studies which adjusted for SES than those that did not (Kritzinger et al. 2009; see also Lin et al. 2007; Harling et al. 2008). Furthermore, WHO (2012) estimated that there were 339,000 new HIV-positive TB cases in 2011 in South Africa, bringing the country's HIV prevalence in incident TB cases to 65 per cent, the highest level of co-infection globally. Furthermore, there seems to be a growing trend in levels of co-infection, with 2011 estimates being 5 per cent higher than those for the previous year (WHO 2011) and those identified by Corbett et al. (2003). On the positive side, multidrug resistance still appears relatively low compared to other high-burden countries. MDR-TB was found in 1.8 per cent of new TB cases and 6.7 per cent of retreatment cases. Another recent national survey (see Weyer et al. 2007) also commented at the relatively low rate of MDR-TB in South Africa, but they note that drug resistance is higher in retreatment patients as well, with them being 2.3 times more likely than new patients to have an increased risk of drug resistance. They also point to the relatively high rates of HIV-co-infection, with this varying from 28 (Western Cape) to 72 per cent (Free State) by province, with Mpumalanga and North West having over two-thirds of cases. They conclude (Weyer et al. 2007, 1127) that 'a history of sub-optimal TB control together with the rapidly progressing HIV epidemic has created a fertile environment for transmission of drug-resistant TB in South Africa'. This comment applies particularly to those living in rural and informal settlements (see also SA Dept

![Figure 14.2](https://example.com/figure14.2.png)  
*Estimated HIV prevalence in new TB cases, 2011 (WHO 2012)*

of Health 2007). Hence, while MDR-TB rates are still relatively low, there is no room for complacency.

Overall, these factors have led to life expectancy declining by almost 20 years and infant and maternal mortality at their highest rates ever. Mean life expectancy is 48.4 years for men and 51.6 years for women today, implying that most adult South Africans are dying in the economically active period of their lives (Karim et al. 2009). While these issues are clearly a national problem, local effects can be identified. A community-based study in Johannesburg found a 2.5-fold increase in overall TB notification rates culminated in annual rates exceeding 1,400 cases per 100,000 persons. This is double the national rate, approximately nine-fold higher than the TB notification rate for sub-Saharan Africa and 280-fold greater than that for the United States. The epidemiology of TB in this community has changed profoundly over a short period of time. Historically, TB notification rates in this community have been highest among persons older than 60 years of age. However, in 2003–2004, the rates were highest among persons aged 30–49 years, indicating a major shift in the burden of disease to individuals in the economically productive age groups who also have the most dependents (Lawnet et al. 2006).

XDR-TB and the socio-political challenges this brings are especially noticeable in South Africa. In this country, XDR-TB first emerged at a rural hospital in Tugela Ferry, KwaZulu-Natal. Of the 1,539 individuals tested for tuberculosis from January, 2005, to March, 2006, 542 had at least one culture that was positive for M tuberculosis. Of these 542 with confirmed tuberculosis, 53 had XDR tuberculosis. The median time of death from sputum collection was 16 days (range 2–210 days) for the 52 of 53 patients who died. Concern about hospital-acquired infection was triggered by the findings that 26 (55 per cent) of 47 patients with XDR tuberculosis had never been previously treated for tuberculosis and 28 (67 per cent) of 42 had reported a recent stay in hospital before their tuberculosis diagnosis (Jassal and Bishop 2009). As Singh et al. (2007) note, system characteristics are as important as patient-related ones, with poor institutional infection control procedures being indicted. Many hospital patients are often co-infected with HIV
and other opportunistic infections. This issue of cross-infection is often worsened by those with TB being made to attend outpatient treatment for receipt of DOTS tablets on a daily basis in some jurisdictions. This demand means that spread of the bacillus may be assisted, especially where immune-compromised patients mix with those with active TB. In addition, the daily DOTS strategy may lead to default on treatment as might that of involuntary hospitalisation for those with XDR-TB. Atkins et al. (2010) in their study of Khayelitsha, Cape Town, call the former treatment coercive. A similar comment may be made about involuntary hospitalisation for XDR-TB. Singh et al. (2007) argue that this tension between individual rights and public health must favor the latter.

Default is a serious matter with such a contagious disease as TB. Brust et al. (2010) demonstrate from their analysis of treatment for MDR-TB in KwaZulu Natal that 21 per cent of initiated patients defaulted, 17 per cent failed treatment and another 18 per cent died during treatment. Botha et al. (2008a, 2008b) in a study of Cape Town derived a default rate of 17 per cent. When examining why patients were lost to follow-up, the main issues were found in finding individuals to interview (24 per cent had died and 45 per cent were not found). Of the 18 patients interviewed, 10 defaulted because of system problems (e.g., inconsistent test results, files missing) and 8 for personal reasons (e.g., denial that they interrupted treatment or started it late, considered TB not serious). A similar figure of 16 per cent defaulting was found in a recent study in the Western Cape (Jacobson et al. 2011).

Treatment success depends therefore on the system as well as the patient. Treatment of MDR-TB and XDR-TB requires a longer duration; is considerably more complicated, expensive, and toxic; and results in lower treatment success rates. HIV-infected individuals undergoing treatment for MDR-TB have lower rates of treatment success and higher mortality rates than do HIV-uninfected patients. One study of a case series of patients with MDR-TB in South Africa found that the treatment success rate for HIV-uninfected patients was 53 per cent, compared with 38 per cent for HIV-infected patients. These treatment success rates, even among HIV-uninfected individuals, are significantly lower than the international norms for a well-functioning MDR-TB program (Andrews et al. 2007). As indicated above, treatment success of both ‘normal’ and drug-resistant TB is not only relevant for the individual patient but for public health and the economy in general. Hence, understanding and addressing challenges impeding success at the health system level are important.

But the patients’ broader social context cannot be ignored. In a review of patient perceptions, Munro et al. (2007) point out that for most, distance and access to available transport as well as their physical condition affect treatment uptake. Other issues concern long waiting times, queues, lack of privacy, inconvenient appointment times, and the poor upkeep of clinics’ health care facilities. TB also has consequences for employment and there is often a tension between adherence and work. Economic barriers are many. The influence of community members or peers on treatment-taking behaviour and the strong influence of stigma among family and friends may lead to TB patients hiding their diagnosis and feeling guilt and shame because of the disease with consequences for later productivity and the care of children.

**Experiencing TB and its Treatment at Urban and Rural Sites in South Africa**

In order to contribute to the knowledge base needed to respond better to the TB epidemic, an analysis of patient experiences of TB and its co-infection with HIV was recently carried out in two urban and one rural area in South Africa. Part of a larger project on access to health care services, a patient-centred exploration of TB treatment and antiretroviral therapy (ART) was undertaken (see Chimbindi et al. 2012, Fried et al. 2012). Forty-five patients were interviewed in Bushbuckridge (Mpumalanga), Soweto (Johannesburg, Gauteng) and Mitchell Plain (Cape Town, Western Cape) on their life histories, with a special focus on their experiences with TB and access to related health care. Most of these patients were interviewed twice to further clarify and expand on their narratives. In addition to the patient interviews, 22 TB providers from the same health facility locations were also invited to share their experiences within TB health care provision and with TB patients. They were also specifically asked about the challenges patients are facing in accessing TB treatment.

In the following analysis, all names mentioned are pseudonyms to protect the identity of our interviewees.

Some patients describe their many months of receiving treatment for TB. They emphasise the complexity of the treatment, especially in the context of poverty and the high rates of HIV co-infection, but also of the positive impact the availability of treatment has had on their lives. Treatment becomes the dominant dimension in life, impacting on social and economic life. For example, Nolwazi Mthembu, a 37-year-old, HIV-positive widow and mother of one surviving child in Bushbuckridge describes her experience after the HIV-related death of her husband and second-bam child:

Yes, they checked me for TB and HIV as well from the clinic. They referred me to the nearest clinic to receive the TB treatment for six months and I became well again after taking the treatment for six months. Then, they referred me to a (nearby) Hospital that in January 2008 I should go there in regards with my HIV status.

Thulani Zondo, a 36-year-old Soweto resident, is on ART and TB treatment, but defaulted the former. He used to have a regular employment in the industry. and suspects that he lost his job due to his illness. Now he earns money by being self-employed, selling ice cream. Describing the actual process of receiving DOTS, he says:

When you get there, if you’ve just been infected, they give you a card and some pills to take or you give them pills to take in the clinic and you have to come to the clinic every time to take the pills. But if you know how to take the pills, they give you those pills until you recover. Then, after you have recovered well for them, they then give you more pills to take on your own. And then when it comes to the number of days that you should come and collect another batch of treatment. For example, they can say next week Monday or Tuesday you should come to collect another treatment. And then they change them after some time when they see that you are committed into taking your treatment.

A clinic nurse in Bushbuckridge aims to highlight the clinic’s flexibility in enabling patients to fit the long-lasting treatment into patients’ lives:

If they are having a problem of not coming every two weeks, they do explain to us so that we increase the treatment. But we stress that usually we want to see the improvement when they come every two weeks. But sometimes they give reason ‘but I am working, I don’t have a chance, please increase this treatment for me,” so we increase.
Another man, 51-year-old Samuel Mkhongo, was diagnosed with HIV in 2007 and now receives ART as well as TB treatment. While both he and his wife are unemployed, he gets strength from his religion and from the support of his wife.

I'm just living my life, doing what I can – trying to gain stamina, and drinking Magwe [a traditional non-alcoholic drink]. And when I was at the TB side, we were taught that when you are on treatment, you are not supposed to miss any dose. And you are also not supposed to drink any traditional methu (medicine). That's what I always knew from when I was at the TB side when they educated us every day. (...) I was at home; they gave me appointment dates for follow up and to collect treatment. They would tell me that I was taking it properly. So I was taking it from home until they told me that I have finished.

Mvelo Moyo, also 51, a divorcee with one child who learnt of his HIV status in 2007 and had to quit his job because of deteriorating health, speaks of his treatment experiences that were also influenced by strong family support and a continued use of a traditional healer.

I am feeling fine; I am feeling very much better. I am not really fine but I can work, even at home. I am working on my own. (...) I was unable to drive, my only problem are my legs, because at some point, (they) are having numbness and it's continuing. It was also in the hand, but now it's not that much. It is only left in the legs but in terms of life, I am feeling very much better because of the HIV and the TB treatments. I am able to do everything at home, I even do washing my clothes, ploughing and also building houses (for the) chickens when it's necessary.

A 38-year-old Soweto mother of a 16-year-old son and 13-year-old daughter, Thabisa Zulu finished her schooling at standard nine. In the past, she used to have a regular job but is now self-employed. She describes her complicated diagnosis and successful treatment in the following story:

I went for the TB test when I was losing weight. I had those signs, I was not eating and I was sweating. So I said, these are the symptoms of TB. Here they are, they are written at the clinic. I see them, I said alright let me go for a TB test. And then they give you a small plastic bottle to put sputum inside it and bring it back to the clinic. Then, when I want to get my results, my results were negative. But the signs are saying I am losing weight and all that. So, I asked why don't you get it. Then they said, let us take another sputum (sample). They took it three times. Going back to the clinic, the last test was taken by the doctor from the hospital. So he checked everything with the blood test and he discovered that I had TB of the blood. He told me that I will attend TB treatment. He asked me which is the nearest clinic? You must go there and get your treatment. He started me with multivitamins and gave me a referral letter to go and take TB treatment. That is how I got TB; I found that everything was O.K. with my treatment. I went there every day to go and drink. (...) I think it was for two months, then they started to give me treatment for two weeks and every time after two weeks. And they would give me a green card to mark if I have taken treatment and if I haven't taken it. (...) It was for nine months and I finished it. They tested me and I was cured and I started my ARVs.

All the above stories speak of the promises of a successful TB therapy and the importance this has for the survival and ordinary lives of infected people. However, they also indicate some of the challenges related to treatment – the complexities in adjusting treatment to the daily life of people, the importance of traditional and religious beliefs as well as social support networks, the economic costs of treatment, difficult diagnosis and other health care provider challenges including the high level of HIV co-infection.

Fifty-three-year-old John Mayibuye, originally from Mozambique and working since the age of 10 in Johannesburg's mining industry, describes his approach to the double diagnosis. The married father of two children, despite being on TB treatment, also uses traditional medicine and considers himself a traditional healer and expresses his thoughts on the best treatment approach.

As I am going to complete my TB course, I will go for check-up after this (for HIV). (...) I don't want to mix the treatments because I am still taking six tablets for every day and it will be too much to take another treatment, so I have to finish this one first. I know that when I get to mix the treatments, it would not come along. I have to go step by step.

There are many difficulties in accessing care. Some of these are also related to patients' knowledge and attitudes. One TB health care provider in Bushbuckridge considers stigma and inconvenience as some of the issues, leading to delay: 'You know, maybe they don't want to be seen when they are coming here, and sometimes they are just afraid of this long queue.'

However, it is not only health care providers who observe a delay in seeking treatment, often for competing interests such as work. John Mayibuye describes his own experience:

I was suffering from this disease, TB and I didn't know in the beginning that I was suffering from TB. I felt tired when working, even when walking. And I didn't know what was what, so they took me to see a doctor. He examined me, he said that I have water in my stomach and I have to go for X-ray. But I didn't go for X-ray till the illness became worse and I got bedridden. My son called his mother at home to fetch and they took me to (the nearest) hospital.

Similarly, Mlumbuzi Nhabe, a father of three children, had to stop working due to his illness, but took months to realise its seriousness:

I was coughing, feeling hot when it's cold, and sweating and feeling cold when it's hot, and shivering. Until I came here to the clinic where I was diagnosed with TB. (...) It just took me over four months, if I am not mistaken. (...) I became ill for a long time while in Joburg. I was thinking that it was just a cough and (only when) I realised that it is becoming worse, then I came home (and went to the clinic).

This delay in seeking care does not only influence people's own well-being and the individual's chance to get healed, it also impacts on the treatment success rate. However, while attitudes can play a role in initiating contact with the healthcare system, there are also barriers once patients have started treatment. Treatment delays and barriers may come from lack of knowledge, transport issues and the debilitating nature of the illness. Concentrating on those affecting security and well-being, a TB co-ordinator talks of social and economic insecurity and the lack of financial resources:
Because the issue of crime, I think it also contributes to the challenges that we are having. Because in our community, we have got the challenge of poverty where you find that at times people have got to take the treatment on an empty stomach. The food supplements that we are getting, it's only the (...) soft porridge type (...) Although it does help, but it's not enough.

Insufficient nutrition is especially problematic since it increases the chances of severe side effects and related treatment interruptions.

Others just default and then others, when we did the follow up treatment, you find that some are not taking treatment who are saying that we don't have something to eat, and this treatment is making us to be very hungry, so I can't take it because I don't have something to eat.

Similar issues are also identified by a DOTS treatment supporter in Mitchell's Plain:

sometimes, they default because they say that they can't eat the tablets because they are hungry, they don't have food, that's why they default the treatment. The others, they said "No, we are working; we can't go to the clinic every time." We just explain to them, "we are here for you, that's why we are the community DOTS (supporters). To help those who are working, after work you just come to me and take your tablets and every day you must do that." (...) The other (patients), maybe they are far away, they are too far from the clinic, they don't have the money to come, they have to take the taxi. They can't walk every day, now it's raining. The others, even day before yesterday, it was raining, they didn't come. Yesterday, we just go to them to recall them, "Why didn't you come?" They said "It was raining, when can I go out, go to the clinic, when it is raining?" We said, "But it is your health." (...) It was really raining hard, but they are supposed to make a plan. Don't know about a plan, but they are supposed to eat their treatment each and every day.

These insights by health care providers support the findings by Munro et al. (2007) about the ways in which poverty-related financial resource constraints can undermine physical access (e.g. transport) and treatment adherence (e.g. nutrition). These factors are seldom articulated by patients, except for their immediate physical condition. However, besides these difficulties there are also factors more directly linked to health facilities and the actual provision of services with staff shortages and overworked staff being often less than sympathetic. A resource-limited setting with patients having difficulty making ends meet can lead to communication difficulties, lack of trust and provider insensitivity, worsening the situation of suffering from TB.

For example, 38-year-old Lesedi Ledwaba from Johannesburg was diagnosed with an STI and HIV in 1996 and started a TB DOTS therapy. The mother of one son, she lives separated from her abusive husband and found strong support in her elderly neighbour, who treats her like her adopted daughter. Due to a lack of money for school fees, Lesedi Ledwaba had to leave school after standard four and now earns her living by doing laundry and ironing in other people's households. Being on TB DOTS and ART, she describes her experience of diagnosis, treatment side effects and subsequent complications within her clinic:

With TB, I don't know because I was sent there by the professional and they gave me two bottles for sputum. Then they tested my sputum and it all came back negative. Then the last test showed that I have TB. Then they started me on treatment for TB. Maybe I took them only three times because those big ones ([tablets]) there are so fine for me. They used to make me sick because I used to vomit after taking them. Then I told my adopted mother that I am no longer going to the clinic to get the TB treatment because it is making me sick and I vomited all the time. Except for that this HIV treatment needs me to eat before I can take it, but now -- because after eating I vomit because of these TB tablets -- then I have to stop the treatment.

Perhaps due to a lack of trust, Lesedi Ledwaba did not share her concerns with health care providers supervising her TB DOTS:

Then when I came back here the professional nurse shouted at me and told me that I will even stop my ARV treatment. (...) She said to me, "Why are you infecting me with TB?" shouting at me as if I am a child. But because I am a quiet person I kept quiet, (while she was) hanging her hand on the table at the same time. Then she took my file and we went to the TB side. (...) And when we got there we found another nurse lady and she told her that if I do not come for treatment that side then she will stop me from taking the ARVs also. And all that time I was quiet and I said nothing. (...) Then afterwards, when I left this place, on my way home I felt so much, I couldn't feel myself walking. Even where I stay now, my adopted mother knows that you can be hurt on me, but not that hurt because I am not supposed to be stressed because of my health. What the professional nurse did to me, it was hurtful.

All these experiences also highlight the additional complications faced by a TB treatment programme in countries with very high-levels of HIV co-infections. In South Africa, where more than 60 per cent of all people with TB are HIV-positive, this is especially relevant and needs specific co-ordination efforts between the two, usually parallel implemented, health care provision areas in a resource-limited environment. One key ingredient in enabling continuing access to TB DOTS is the availability of sufficient resources, including necessary drugs and health care staff. Commenting on the former, a TB programme co-ordinator describes:

Yeah, I think TB drug supply is ... it's adequate. Although we did have a little bit of a problem, but that was last year -- we had a shortage of streptomycin -- that is a TB injection for those that are on re-treatment and we had a little bit of shortage of rifampicin as well, that is your rifam. But it was a specific rifampicin -- 150 75%. So we had a shortage of that, but that was for about four months, but it was four months too long, you know? (...) But we had a way of dealing with that because we were going from facility to facility to buy and borrow from this facility and supply this facility and ... it was a strain, but it did work, we didn't have a situation where people completely did not have treatment.

A nurse from Mitchell's Plain indirectly illustrates the resource limitation of staff shortages leading to increasing wait times, and thus perhaps reducing patients' willingness to regularly visit health facilities, especially at a later stage of treatment once their symptoms have improved.
It's never more than an hour, I would say, it's never more than an hour. (…) It's only, the only busy day that they will find themselves waiting is on Monday, when we've got a doctor and on Fridays where I am busy doing Mantoux's on children. So in between then, they will find themselves waiting especially the ones that are on Streptomycin or MDR, or Kanamycin. Those are the only ones that find themselves waiting. (…) Most of them are very impatient, but for some reason they manage to wait. Very few will say sister I can't wait I'll come back or very few would disappear for good. Some of them do wait, really (…).

Treating MDR-TB patients in hospital or community setting adds more problems, especially related to infection control.

And of course we have patients like our special patients, the MDR patients. In Bushbuckridge, we have 39 MDR patients that are actually in the community and we have three … two XDR patients and the one that is actually still on investigation but we are afraid … (ii) looks like we're going to have three XDR patients. And all of those patients are in the community. So they have to be visited, and you know, re-adherence is strengthened on them and … re-educating on how to isolate these people, not in a way that they can actually feel like they are not wanted.

These experiences of TB and its treatment in the context of South Africa provide voice to those dealing with this epidemic, its impacts and context. South Africa is a middle-income country with great wealth disparities, exacerbated by its apartheid years. Resource limitations prevent good infection control, especially with MDR- and XDR-TB. Providers are stretched and while they recognise the economic pressures on patients, they can do little to mitigate them. Patients see their physical challenges and how complicated care is and how that, with possibly ART, be fitted into economically deprived but often socially resilient lives (Fried et al. 2012).

Discussion and Conclusion

TB is back with a vengeance, although there have been some changes in locality and significant recent improvements as documented by WHO (2012). Treatment and infection control are central in managing this treatable disease. For this, a constant supply of quality-assured anti-TB drugs is fundamental. Directly Observed Treatment, Short-course (DOTS) is the systematic application of standardised and supervised drug therapy, along with diagnosis by sputum smears. DOTS has been practiced all over the world since 1999. But DOTS coverage is not the same as DOTS treatment and estimates of incidence are difficult to achieve (see Attaran 2005). As we have seen, DOTS does little with respect to drug-resistant TB and may provide a false sense of security or complacency. Questions have been raised over the efficacy of DOTS over other TB treatment approaches (see Davies 2003) or that direct observation enhances cure rates (see Volmink and Garner 2009). There are serious concerns as well over the accuracy of sputum tests. In a study in South Africa, Hassim et al. (2010) showed only one third of culture positive patients were identified by smear. Depending on its implementation, DOTS also has implications for civil rights. The 'policing' of patients through direct observation and the uses of coercion and detention with MDR- and XDR-TB may delay treatment (see Coker 2003) and be difficult to enforce in resource-limited settings, while significant ethical issues remain (see London 2009). Such settings may also compromise infection control, making the impacts of the disease worse for its sufferers and their dependents. Infection control in countries undergoing rapid societal or political change or with large, poor and poorly housed populations is likely to be minimal. The experiences of our respondents in South Africa are likely to change slowly because of the inequitable development and distribution of resources. Low economic status, social stigma and the denial of opportunity will continue and reinforce the challenges in such societies and populations. The co-infections of TB and HIV result in opportunities, too, as there are similarities in their treatment regimes and thus potential for pooling resources (see Maher 2010). But as Horton (2009) noted, "progress towards the Millennium Development Goals has been slow and uneven. Inequities in health are deep and intractable. Donor funding is unpredictable. International institutions suffer pervasive democratic deficits - the views of low-income and middle-income countries are too often marginalised or excluded". Furthermore, 'evidence from past economic crises gives us reasonable precision about what is likely to happen … Government expenditures on health will be squeezed and likely fall, contributing to worse health outcomes. Household income to pay for health will drop. Insurance protection will decline. The cost of medicines will probably increase (because of currency devaluations). Patients will switch from the private to the public sector, putting an often unbearable burden on government-funded health services' while at the same time economic productivity is further compromised. Investing in public health needs to become a greater global priority since development of any kind is not possible without treating the diseases that sap the strength, hope and energy of individuals, communities and regions. TB is one of these.

References


Stuckler, D., Bass, S., McKee, M. and King, L. 2008. Mass incarceration can explain population increases in tuberculosis and multi-drug resistant tuberculosis in European...


