"I get frustrated and sad when people die, whilst there is treatment available for them that could have made them better and allow them to live on for many good years and enjoy their lives."

— MSF medical staff member in Nchelenge district, Zambia.

MEDECINS SANS FRONTIERES

TB AND HIV
THE FAILURE TO ACT

TB AND HIV
THE FAILURE TO ACT

EXECUTIVE SUMMARY

Tuberculosis (TB) and HIV/AIDS are intricately linked. There are currently 11 million people 'co-infected' with both diseases and half of all deaths of HIV- positive people are due to TB.

Although there is growing international recognition of the nature of the relationship between the two diseases, there is a massive failure to respond to the dual epidemic in an integrated way. Despite clear statements from the World Health Organisation and others on the importance of implementing a joined-up approach, TB and HIV programmes continue to work in isolation from each other.

This must change. For people infected with both HIV and TB, to treat one disease is not enough. Patients receiving HIV treatment can still die of TB, and patients being treated for TB often still die from AIDS.

Médecins Sans Frontières (MSF) currently runs TB projects in 44 countries and HIV/AIDS projects in 33 countries around the world. Based on our experience on the ground, MSF believes that the global response to these diseases remains shockingly inadequate. Urgent action is needed to combat TB and HIV and stop the rising tide of needless deaths.

The most important steps to be taken are:

- Routine HIV testing and care must be made available for all TB patients;
- All HIV/AIDS patients must have access to early diagnosis and treatment of TB;
- Six month TB treatment regimens must be used and the 'DOTS' approach must be adapted on the ground to cope with the effects of the HIV epidemic;
- Support for research and development is desperately needed to ensure that better tools for diagnosing and treating TB are found, and in the longer term that effective TB and HIV vaccines will be developed.

INTRODUCTION

This report describes MSF's experience of treating people who are infected with both HIV and tuberculosis (TB). Through programmes in Africa and Asia, MSF is struggling to ensure that people with these diseases receive proper treatment and no longer die unnecessarily.

Effective TB treatment became available in developed countries 40 years ago and it is more than 10 years since effective AIDS treatment was introduced in the West. Yet the vast majority of those infected with these two diseases today live in the world's poorest countries and still die needlessly due to a failure of disease diagnosis and lack of access to the treatment.

Governments and institutions across the globe have committed to making dramatic reductions in the rates of both diseases and to ensuring that everyone receives the treatment they need. However, MSF's experience in trying to provide care is that there is little evidence of progress in the poorest countries and communities where these epidemics have a fatal grip. In Africa, of all the people infected with both diseases, fewer than 1% are getting the drugs that they desperately need [1].

MSF has shown that it is possible to treat people with these infections in the most difficult settings, through using innovative ways of finding, diagnosing, and treating patients. But we are hampered by the outdated and ineffective tools available for diagnosis and treatment and a lack of research.

The aim of this report is to highlight the effects of these two diseases on people's lives and to share MSF's field experience: what works in attempting to provide treatment and combat these dual epidemics, what is failing, and what urgently needs to be addressed to prevent many more people dying.

Note: names of some patients have been changed to protect their anonymity.

ZAMBIA

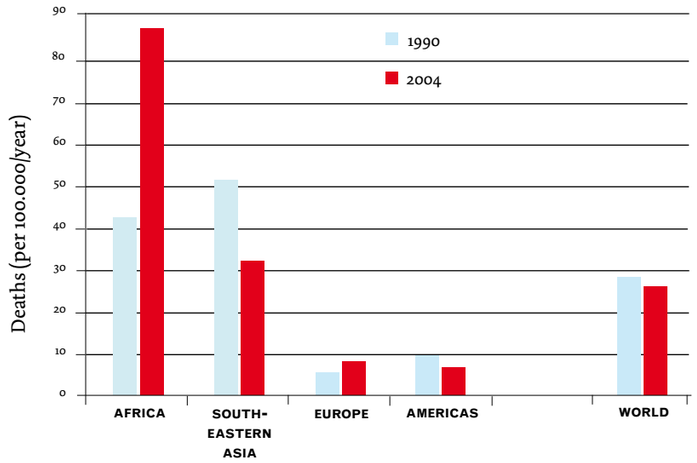
An estimated 1 million people in Zambia are living with HIV/AIDS. In rural areas health services are limited. In one of these areas, Nchelenge district in the northeast, MSF is providing antiretroviral treatment to over 1,000 people living with HIV/AIDS. Each month, there are 45 new patients. MSF screens these patients for TB and works with Zambian health authorities to initiate further treatment in case of co-infection.

Photos: Pep Bonet

1

TB AND HIV:
A DEADLY COMBINATION

Tuberculosis kills around two million people every year. TB is the major killer of people living with HIV: up to half of all deaths of HIV patients are due to TB. A patient with both diseases can be four times more likely to die during TB treatment than someone being treated for TB alone.



TB RATES HAVE INCREASED DRAMATICALLY IN AFRICA:
(figure reproduced from 2006 WHO report Global tuberculosis control: surveillance, planning, financing.*)*

The spread of HIV is fuelling the rise of TB in many regions of the world. In parts of Africa, more than half of those infected with TB also have HIV. MSF doctors in countries with the highest HIV prevalence rates, such as Lesotho and Zimbabwe, find that over 75% of TB patients are HIV-positive.

> *"The situation is very urgent. TB is the biggest silent killer of HIV patients in Africa."*
> **— Dr Charles Ssonko, Medical Team Leader for MSF, Zambia.**

While HIV rates are not as high in most of Asia, TB and HIV remain major problems among 'high risk' groups such as intravenous drug users and sex workers. Rising HIV rates, along with increasing resistance to TB drugs, mean that poorer countries in Asia struggle to control these diseases.

For people infected with both HIV and TB, to treat one disease is not enough. Patients receiving HIV treatment can still die of TB, and patients treated for TB often still die from AIDS.

> *"It was only after the TB that they discovered that I was HIV positive. The TB exposed my HIV."*
> **— Mary, 53 years old, Nigeria. Co-infected patient.**

TB AND HIV

By the end of 2006 there were an estimated 39.5 million people living with HIV worldwide. In that year 2.9 million of them died. Currently, 9 million people develop TB each year and 2 million die of the disease. 11 million people are infected with both diseases[2].

The HIV virus itself doesn't kill. It weakens the immune system by destroying CD4 cells, which usually defend against infection. Most people will remain healthy for many years after contracting HIV. Only after around five to ten years, when the virus has severely damaged the immune system, do people progress to the next stage – AIDS.

AIDS is diagnosed when a defined set of clinical conditions are found in a person infected with HIV. These conditions are mostly infections that occur once the immune system is unable to fight them – so called 'opportunistic infections'. TB is one of the most common 'opportunistic infections' in people with HIV.

TB is caused by a bacterium called *Mycobacterium tuberculosis*. Infection usually happens by inhalation of bacteria released when an infected person coughs or sneezes. Globally about one in three people are infected with TB, but most will not become sick since the immune system in healthy people is usually able to prevent the infection from progressing to the active disease.

When someone is co-infected with TB and HIV, the damage to the immune system caused by HIV means that they are less able to fight TB infection. As HIV progresses, the immune system becomes weaker and the risk of developing active TB disease increases.

As a result, people with HIV infection are up to 20 times more likely to develop TB disease than people who are not infected with HIV[3]. For AIDS patients who take antiretroviral treatment the risk of developing TB is much lower, but remains 4-8 times higher than people who do not have HIV[4].

In addition, due to their weakened immune system, TB more often infects areas of the body outside the lung in someone with HIV, leading to 'extra-pulmonary TB'. For example, it can infect the spine (which can cause paralysis), the kidneys, the lymph nodes, or the lining of the brain (TB meningitis). Many of these forms of the disease are difficult to diagnose and are much more common in people with HIV.

TB causes death in a number of ways. It can spread through the infected organ (lung, kidney, bone, brain, etc) and stop it from working. In TB of the lung, much of the lung tissue can be destroyed. TB not only weakens the immune system further, it also causes loss of appetite so that patients stop eating and become emaciated. This further reduces their ability to fight infection.

2

TB AND HIV CAN BE TREATED

Once someone with HIV is infected with TB, effective treatment is still possible. The sooner people with HIV start TB treatment, the greater chance they have of surviving. Cotrimoxazole, *an antibiotic, must be added to the treatment of all TB patients known to have HIV; this simple addition can reduce the death rate during TB treatment by 40%* [5].

Similarly, the sooner co-infected patients start to take antiretroviral (ARV) drugs to treat HIV, the better the chances of survival and cure. Without ARVs, co-infected patients are likely to die from TB or other infections during or soon after TB treatment. A study in Thailand found that 88% of co-infected patients who received ARVs were alive after 3 years of treatment – compared with just 9% of patients who, before ARVs were available, received only TB treatment.

It is therefore vital that TB patients are tested for HIV and that they are put on effective treatment if found to be HIV-positive. Yet, shockingly, only 3% of co-infected patients in Africa are tested and found to be positive – and only 0.06% receive anti-retroviral treatment [1].

When patients receive treatment for their illnesses, their lives can be transformed, and they start to hope and plan for their and their family's futures.

> *"Just after I was tested for TB and HIV and when I was so very ill, I felt so depressed about being sick and not being able to provide for my family that I thought about suicide a couple of times. When I heard about ARVs and that treatment for HIV patients is possible, I started to get hope. I started the ARV treatment in November 2005 and started feeling better quickly. Now, I feel much better. I still have HIV of course, but with the ARVs I am able to work and provide for my family. For the near future I hope to earn some money to buy fertilizer for my land, in order to be a better farmer. One day I hope to get back to work as a salesperson – that is what I did before I got sick. I have a family of seven children."*
>
> **— Peter, 40 years old, married, seven children, Zambia. He had been co-infected with TB and HIV.**

2.1 MSF'S EXPERIENCE OF TREATING PATIENTS WITH TB AND HIV

MSF has been providing care for people with TB since the early 1970s. The focus has largely been on treating people in areas with no government TB programme and targeting groups neglected by their governments. These groups have included nomadic populations in Sudan, war-affected people in Afghanistan, Somalia, and Chechnya, and prisoners in Russia with multi-drug resistant TB. In 2005, over 17,000 people were treated for TB by MSF teams in 94 projects in 44 countries. Many more patients were referred by MSF for treatment within national TB programmes.

MSF began caring for HIV patients in the early 1990s and started providing ARV drugs in 2000. Since then, MSF has successfully provided treatment in many countries around the world, even in remote and conflict affected areas. Thanks to a major campaign for access to medicines, huge reductions in the prices of HIV drugs have allowed many more people to start treatment. Today there are over 80,000 people on HIV

LIVING WITH TB AND HIV

Through our programmes, we witness the effect that living with HIV and TB has on individuals and communities. As well as the physical effects of their illness, people have to deal with stigma from friends, family, the community, and, all too often, the health-care workers who should be supporting them. People living with HIV/AIDS and TB are often very poor and their situation is worsened if they are too sick to work or are refused work because of the stigma attached to their illness. Often they live far from health centres and can ill-afford the costs of transport and the time away from work to get care. If they do access care it can often be financially crippling for them and their families if they have to pay for drugs or treatment.

On top of social stigma and the costs of health care, it is also difficult for people to get a timely, accurate diagnosis and to access treatment. This effectively means that HIV patients are denied care for TB in many settings.

> *"I felt really down and was dating a guy and we decided to go to the clinic together. We both tested positive [for HIV] in July 2001. For a whole month I couldn't move out of bed. My mother had to look after me, clean my body, mop me and feed me. I was coughing a lot and couldn't do anything for myself. But somehow I picked up again and I went to Lagos General University Hospital. All they could do was to give me multi-vitamins and supplements. I wasn't tested for TB. I think they just saw I had HIV and they didn't bother."*
> **— Diane, 26 years old, Nigeria. She is co-infected with TB and HIV.**

> *"I had diarrhoea, fever, and my lymph nodes were swollen. I thought it would pass. So I did nothing but I became weaker and weaker. I suspected it was TB but I could not afford a treatment. I heard about the MSF clinic where you get treatment for free. Elsewhere the treatment costs a lot of money.*
>
> *The diagnosis was TB and I started treatment. In the beginning I felt a bit giddy and my fingers tingled. But it didn't last long. The treatment was not so difficult. When I came here I did a test for HIV. When they told me I was HIV+, I was in pieces.*
>
> *Every month I come to the clinic for my pills. If I take my pills it will go fine. I don't want to think about death. When my husband was sick his family didn't tell me that he had TB and that he was HIV+. They said he had a liver disease. He had a TB treatment but he didn't take his pills regularly. Then he stopped the treatment. He passed away at home.*
>
> *If I take my pills carefully I can do things and care for my children. Now I'm already much better. Before I felt inferior because I have the disease I've felt not a complete human being. In the house of my sister, I eat alone. They didn't ask it directly but I knew they preferred it. First it made me sad but now I think they don't know much about HIV|AIDS. I hope one day they will understand more. These days they ask me at their table and sometimes I join them.*
>
> *My husband should have told me openly what his status was. In that case he would be alive today. I wouldn't have the disease. I could have helped him."*
> **— Lucy, 32 years old, Myanmar. She is taking ARVs for her HIV infection and finished her TB treatment a month prior to being interviewed. Her husband died a year ago and now she and her 5-year-old daughter live with her sister. Her sons, aged 7 and 12 years, live with her husband's family.**

treatment in MSF programmes in 33 countries, over 6,000 of them children under 14 years.

> *"I trained here 12 years ago in 1994/95. When a patient came in with HIV he was always put in the last bed by the toilet. Most times nothing was done for them because the belief was that there was no hope for these ones. So I think when MSF came to treat opportunistic infections, and they could actually see these people walk home, it makes a difference."*
> **— Agnes Akporotu, MSF nurse, Lagos General Hospital, Nigeria.**

NIGERIA

In the capital Lagos, MSF is providing over 1,300 patients with antiretroviral treatment. Patients co-infected with TB are treated in partnership with the TB clinic in the Lagos General Hospital.

Photos: Ton Koene


HIV POSITIVE


PHARMACY
SUGGESTION BOX

3

WHY IS TACKLING TB AND HIV DIFFICULT?

Responding to these dual epidemics is a huge challenge, particularly in resource-poor settings where health systems are already struggling to cope. Because many people develop active TB disease in areas where HIV is common, an extra strain is put on weak health services.

Diagnosing TB is already difficult in resource-poor settings, but is especially challenging amongst people who are infected with HIV. Treating both diseases together can be complex and costly and is made more difficult because the established public health approach to treating TB does not serve people with HIV well.

3.1 DIFFICULT DIAGNOSIS

Tuberculosis
The tools available to diagnose tuberculosis have changed little in the last 100 years, due to an abysmal lack of research and development in this area. This means that, with the exception of those patients who are producing large quantities of bacteria in their sputum, most cases of TB remain very difficult to diagnose. The result is that many TB cases go undiagnosed or are diagnosed very late – often too late. Because people living with HIV/AIDS develop patterns of TB disease that are especially difficult to diagnose it is even harder for them to get treatment.

The standard test for TB, known as *sputum microscopy*, was developed in 1882. A sputum sample is collected and stained to show up TB bacteria and then examined under a microscope. While this technique is the simplest way of diagnosing TB, it requires well trained staff and well collected and handled specimens. It will give a positive result only if there is TB in the patient's lungs and they can cough up enough sputum for it to be detected. Fewer than 50% of actual TB cases can be diagnosed using this test[7].

Some patients with TB of the lung do not cough up enough bacteria to be detected by sputum microscopy. This is especially common in people with HIV. A technique called sputum culture is better at detecting low numbers of bacteria but won't find all cases. It is also a slow test, taking anything between one and six weeks to provide a result. Furthermore, because it requires a sophisticated laboratory, it is rarely available in resource-limited settings.

A study carried out at the MSF project in Khayelitsha, South Africa, found that only 16.5% of TB patients, most of whom also had HIV, gave a positive result when tested by sputum microscopy. However, 49% of those patients with negative results had positive results when tested with the more sensitive culture method.

> *"I remember one young man who was very sick. He had HIV and I couldn't diagnose for TB. He was not coughing, but he was losing weight fast. We did the TB tests: sputum test and X-ray were negative. The only thing that made*

me suspect he had TB was his swollen and fluid-filled abdomen. I wanted to start TB treatment but the Ministry of Health protocol wouldn't allow it.
Eventually, we transferred him to Lusaka, the capital city of Zambia. Here he could start the treatment because the Ministry of Health representatives in the capital accepted the local doctor's diagnosis of TB on a clinical basis. The lack of the right diagnostic tools caused a treatment delay of two months.

This man was lucky because he could go to Lusaka. Many other patients cannot move, and die in this process of delay."
— Dr Charles Ssonko, Medical Team Leader for MSF, Zambia.

A chest X-ray will often show signs of TB in the lungs, and can be useful to support a pulmonary TB diagnosis when the sputum test is negative. However, it is still easy to miss TB or to mistake X-ray signs of another disease for TB. This is especially true for patients co-infected with TB and HIV in whom the X-ray signs are rarely typical.

In most remote clinics, the only way that TB can be diagnosed is the microscopic examination of sputum, the clinical skills of the health worker, and occasionally a chest X-ray. Since many people infected with TB do not present with typical symptoms, or with a cough, they are often missed.

"The symptoms of TB are a cough, sometimes with blood; fever; night sweats; and – especially with HIV infection – weight loss. In co-infected patients, weight loss can be the only feature. However, it can be confusing because other conditions associated with HIV can also present with weight loss as the only feature. Hence the difficulty in making an accurate diagnosis."
— Dr Kalpana Sabapathy, HIV Coordinator, Yangon, Myanmar.

CHILDREN ARE PARTICULARLY NEGLECTED

The most neglected of all those suffering from TB and/or HIV are children. HIV cannot be diagnosed in infants without expensive, complex medical equipment. Even when they do not have HIV, the problems of diagnosing TB are greater in children than in adults. It is rare to achieve a definitive diagnosis of TB in co-infected children without equipment that, for most, is out of reach.

"In 1994 we started TB treatment for undernourished children. Young children do not produce sputum and the diagnosis had to be entirely based on clinical judgement."
— Dr Frank Smithuis, MSF Head of Mission and Medical Coordinator, Myanmar.

Children with TB and HIV develop disease more quickly and die more quickly. The drugs needed to treat both TB and HIV are not available in child-friendly palatable liquid forms, nor are tablets small enough for young children to swallow. When drugs are available they are often very expensive.

MSF is increasingly focused on getting children with HIV and TB onto treatment but globally far too little is being done. National programmes neglect children, or leave them until adults are treated. Drug companies see no profit in researching better diagnostic tools or drugs for children in poor countries.

HIV

The challenges associated with diagnosing HIV are quite different in nature to those of diagnosing TB.

Compared with the technical difficulties of diagnosing TB, HIV infection is much easier to identify. The HIV test can be carried out in less than 20 minutes and is very accurate.
However, making sure that people actually get tested for HIV is a major stumbling block. This is partly due to the significant social stigma often attached to being HIV positive. In some cases HIV testing is offered but refused, in others it is simply not available. Unacceptably, in many areas where HIV testing is available, it is not routinely offered to TB patients. Today, many TB patients remain untested for HIV – it is estimated that in Africa only 3% of those who are co-infected actually know that they have HIV.

"Especially TB patients refuse to get tested for HIV. I estimate that only 5 to 10% of TB patients get tested for HIV. When they test positive for TB, patients are relieved that they can tell themselves and their family it was just TB and not HIV."
— MSF clinical officer, Nchelenge district, Zambia.

3.2 TB TREATMENT IS OUTDATED

Lack of interest in developing better drugs has meant that there has been no improvement in the treatment used for TB since the 1970s. The treatment is lengthy and can be problematic in patients who also have HIV. There is a desperate need for shorter more effective treatments. While research has increased in the last few years, there has been no new drug entering wide use in over 30 years, and affordable, effective new drugs remain a distant hope.

There are simply not enough promising drugs in the pipeline and serious funding gaps prevent the development of candidate drug compounds through to clinical trials. Worldwide, only US$20 million per year is currently spent on clinical trials for TB drugs.

TB AND HIV TREATMENT

The drugs used in TB treatment are rifampicin, isoniazid, ethambutol, and pyrazinamide. All four are given daily in combination for the first two months of treatment – the intensive phase.

During the second part of the treatment – the maintenance phase – many countries use a further six months of ethambutol and isoniazid. However, four months of daily rifampicin and isoniazid is far more effective in patients co-infected with TB and HIV[7].

Regrettably, slightly greater expense and concerns that resistance to rifampicin could develop in poorly managed programmes have stopped this protocol from being widely used. This is despite World Health Organisation recommendations. In any case, both treatments are so lengthy that many do not complete their courses.

A further complication is that some of the commonly used ARVs, such as nevirapine, cannot be taken together with rifampicin, a vital part of TB treatment. In poor countries the alternatives to rifampicin are too expensive, and efavirenz (an alternative ARV to nevirapine) is more expensive and cannot be taken in early pregnancy.

In addition, the number of tablets a co-infected patient needs to take each day is high, making it harder for them to stick to their treatment properly. They also tend to suffer from more side-effects from the drugs, which again makes it especially tough for co-infected patients to adhere to the treatment regimen.

"It's not easy taking all the drugs. I take two tablets for my TB every morning at 6 am and then for my HIV I take one in the morning and three at night. I get pains in my legs and headaches and sometimes I don't want to take the drugs, but I do my best."
— Margaret, 40 years old, Nigeria. She is co-infected with TB and HIV.

3.3 LACK OF HUMAN RESOURCES

There are tens of thousands of co-infected people in desperate need of diagnosis and treatment, but very few health-care workers available to provide it. Simply piling more work onto the few existing staff will not work. If TB and HIV patients are to receive effective care there must be sufficient trained and motivated staff available to look after them.

3.4 STIGMA

Stigma can be a major difficulty in responding effectively to these diseases. People are often reluctant to test for HIV out of fear of the disease itself, and fear of the stigma that is attached to HIV.

> *"Patients tell me, I can not handle it to have two major diseases. I have TB now, please stop asking me to get tested for HIV as well. It is too much for me."*
> **— MSF Clinical Officer in Nchelenge district, Zambia.**

Stigma can be deadly. It can lead to people refusing to get tested until it is too late, by which time they are too sick for the treatment to work.

> *"After being diagnosed as having both diseases, Alison died within 6 months. She was already too sick for the medicine to help her. At the end of her life, she had pus in her lungs. They took five litres of liquid out of her chest. It was a terrible way to die.*
>
> *I think if Alison had gone to the clinic earlier to get treatment for her illnesses, she would have been alive today. Alison was a good person, I miss her very much. She left behind four children."*
> **— Sarah talks about her sister Alison (29 years old) who died of HIV and TB co-infection in Zambia.**

As more people are tested and benefit from treatment, stigma is slowly decreasing in some places. However, it remains the responsibility of all involved with care and testing for HIV to ensure that they help address stigma, and help people living with HIV/AIDS to overcome it.

> *"All my family and friends now know I am HIV positive. Many more people are talking about this disease now. The stigma is not so big anymore. In the past that was different, a lot of people died because they didn't want to know they were sick and refused to get tested. For me there is no stigma now anymore: HIV for me is the same as having malaria. It is treatable. I am glad I speak about this disease with friends and family. When I meet other patients who don't, I tell them that when you keep it for yourself, the burden can be very heavy. If you share it, maybe it is easier to handle this disease."*
> **— Masautso, 37 years old, a Voluntary Community Worker, Zambia, who is co-infected with TB and HIV. He helps to detect and take care of TB and HIV patients.**

3.5 ECONOMIC CONSEQUENCES

TB and HIV disproportionately affect poor people who were often already struggling to support themselves before they were infected. Getting sick can be a catastrophe for people who do not have anyone to support them. Whole families are devastated when an income is lost because someone becomes ill and is too sick to work.

> *"Physically, I am not feeling well at all. I feel sick all the time and I cannot work. I am a farmer, I have a cassava and vegetable field. Currently nobody is working the field so we have no income."*
> **— Simon, 36 years old, Zambia. He was first diagnosed with TB and later with HIV.**

If treatment is not free, only the wealthiest patients will be able to afford it. The cost of ARVs and hospital care is such that even the most well-off often impoverish themselves trying to pay medical bills. They can end up being forced to sell land and livestock, to take their children out of school, and eventually to stop treatment.

> *"The TB medication seems to be working because I feel a bit better now than when I first got sick and I have gained weight a bit. I have only been taking the ARVs for three weeks, I don't feel any different yet. I am very happy that I get the medicines for free. If I would have to pay for it, I would be lost. I don't have any money, so I would just die."*
> **— Andrew, 36 years old, Zambia. He was first diagnosed with TB and later with HIV.**

On top of the expense of treatment, the cost of transport can be prohibitive. In poor, rural areas, patients may live very far from treatment centres and as a result are often unable to afford the cost of fares and the time lost working to go and receive treatment.

> *"The treatment is not difficult itself, but financially it is hard. My husband repairs bicycles and is not earning a lot. The transport is very expensive. A big part of his income is used to pay for my bus ticket to the clinic."*
> **— Sonya, Myanmar. She is co-infected with TB and HIV.**

3.6 NUTRITIONAL SUPPORT IS AS IMPORTANT AS DRUGS

Without adequate food and nutrition, drugs cannot cure TB. People with TB and HIV are often malnourished and find it particularly hard to get proper nutrition. It is essential that they are given free nutritional support. This has long been part of the accepted standard for treatment of TB, but is all too often lacking in the response to HIV.

> *"Nutrition is a problem. Even if you get the treatment it doesn't mean you can afford food."*
> **— Simon, community worker in a project for people living with HIV/AIDS, Myanmar. He is co-infected with TB and HIV.**

3.7 DRUG RESISTANT TB

TB will become resistant if it is not exposed to several drugs at the same time. To further reduce the risk of resistance developing, the drugs used in TB treatment must not be available outside TB programmes. In parts of the world where TB drugs have been made available without ensuring they were only used in combination and for TB treatment, resistance to the drugs is common. This means that it can be very difficult in poor countries to test for which drugs will be effective.

> *"In the West, testing for drug sensitivity is more easy. They can take the bug, culture it and test it for which drug it is sensitive to and for which it is not. This option is not available in Myanmar at the moment. In the case of drug resistance you are shooting in the dark because you don't know which drugs will work."*
> **— Dr Frank Smithuis, Head of Mission and Medical Coordinator, Myanmar.**

Where the TB is resistant to most of the routine TB drugs, second-line drugs are needed. These are very expensive, have many side-effects, require a long course of treatment and often have poor outcomes. Most patients in developing countries do not have access to these drugs.

In some countries, multi-drug resistance has become a major problem. Where patients have both resistant TB and HIV the outlook is very poor. Multi-drug resistant TB appears to be on the rise in Africa. A recent study in Kwazulu-Natal, South Africa, where a high proportion of people infected with TB are HIV-positive, showed that 41% of 544 TB patients had multi-drug resistant TB. Of these, 24% had XDR, a form of TB resistant to not only first-line but also most second-line drugs. All except one of these XDR patients died. Major efforts must be made now to address the growing threat of drug-resistant TB, to ensure diagnosis and treatment is available for these patients, to manage care for people co-infected with TB and HIV better to prevent resistance, and to research better drugs for first-line and second-line treatment.

4

THE ESTABLISHED TB TREATMENT SYSTEM FAILS HIV PATIENTS

The traditional approach to TB treatment is called 'DOTS'. DOTS mainly focuses on treating people seen as a risk to public health – those who cough up large numbers of tuberculosis bacteria. Most people infected with HIV and TB do not do this, and so have not been seen as a priority for treatment.[7]

WHAT IS DOTS?

DOTS stands for 'Directly Observed Treatment, Short Course'. Since 1993, this has been the standard of care for TB promoted by the World Health Organisation. Key elements of the DOTS approach include a focus on diagnosing and treating 'sputum-' or 'smear-positive' patients who are a risk since they can spread the disease easily. Treatment is 'short' using a combination of pills for 6 or 8 months. Pill-taking is directly observed by a health worker to ensure that patients take all drugs. This should both ensure cure and reduce the risk of resistance developing.

Unfortunately, a rigid DOTS approach with the emphasis on treating smear-positive patients can actively discourage programmes from treating HIV patients. The effect of DOTS has been that programmes have neglected smear-negative and extra-pulmonary patients. Encouragingly, the more recent 'Expanded Framework for DOTS' addresses some of the failings of the traditional DOTS approach. However, the reality is that things are changing far too slowly.

The slow implementation of new approaches is costing lives. DOTS was not designed to cope with the current situation in countries with high HIV rates. It serves co-infected patients very poorly. A 1999 study of South African gold miners showed that TB rates among miners rose four-fold over a 7-year period despite a good DOTS programme being in place since 1990.[8] The system of direct observation of treatment is a heavy burden on staff and patients and is not evidence-based.[9]

> *"Because of the protocol, smear-negative patients are not followed up, meaning that many TB patients go without treatment. Many of these patients are not only TB patients, but also HIV patients and therefore they die of a treatable disease. But the protocol in Zambia makes it very hard for me to treat these patients for TB, because I need to have a test proving that they have TB. That is a problem because HIV patients often produce a negative TB test, even if they do have it. It is stupid that protocols are so strict that it stops me treating people for TB and preventing them from dying. We can save HIV patients from dying if we treat them for TB."*
>
> **— Dr Charles Ssonko, Medical Team Leader for MSF, Zambia.**

EXPANDED FRAMEWORK FOR DOTS

The World Health Organisation has recognised the inadequacy of DOTS in responding to TB/HIV co-infected people and has identified new approaches to ensure they are not neglected. These include aiming to use only 6-month treatment courses, reducing the insistence on having high proportions of smear-positive patients in high HIV prevalence settings, and ensuring that all non-smear-positive patients still get the best treatment. They also include linking TB treatment to HIV testing, cotrimoxazole provision, and AIDS care including ARVs.

However, in many settings, almost nothing is happening on the ground. For several years it has been clear that the 6-month treatment course is an improvement over the 8-month course, especially for co-infected cases. Yet many countries where MSF works, such as Angola, Republic of Congo, Liberia, Nigeria, Uganda, and Zambia, still use the 8-month regimen.

TB programmes familiar with DOTS have been slow to adopt new approaches, and staff are not receiving appropriate training. This means that it is still often very difficult to get agreement on treatment for smear-negative or extra-pulmonary TB patients, and where treatment is possible there are long delays. These delays can mean the difference between life and death for many co-infected patients.

> *"The problem starts with the inpatients who sometimes can't give a sputum sample. You really have to go over and beg for treatment. It's difficult, particularly at the weekend. The TB clinic shuts at 3 pm and at the weekend so if anyone comes in after that then it is difficult to get drugs."*
>
> **— Dr Helen Bygrave, MSF doctor, Nigeria.**

5

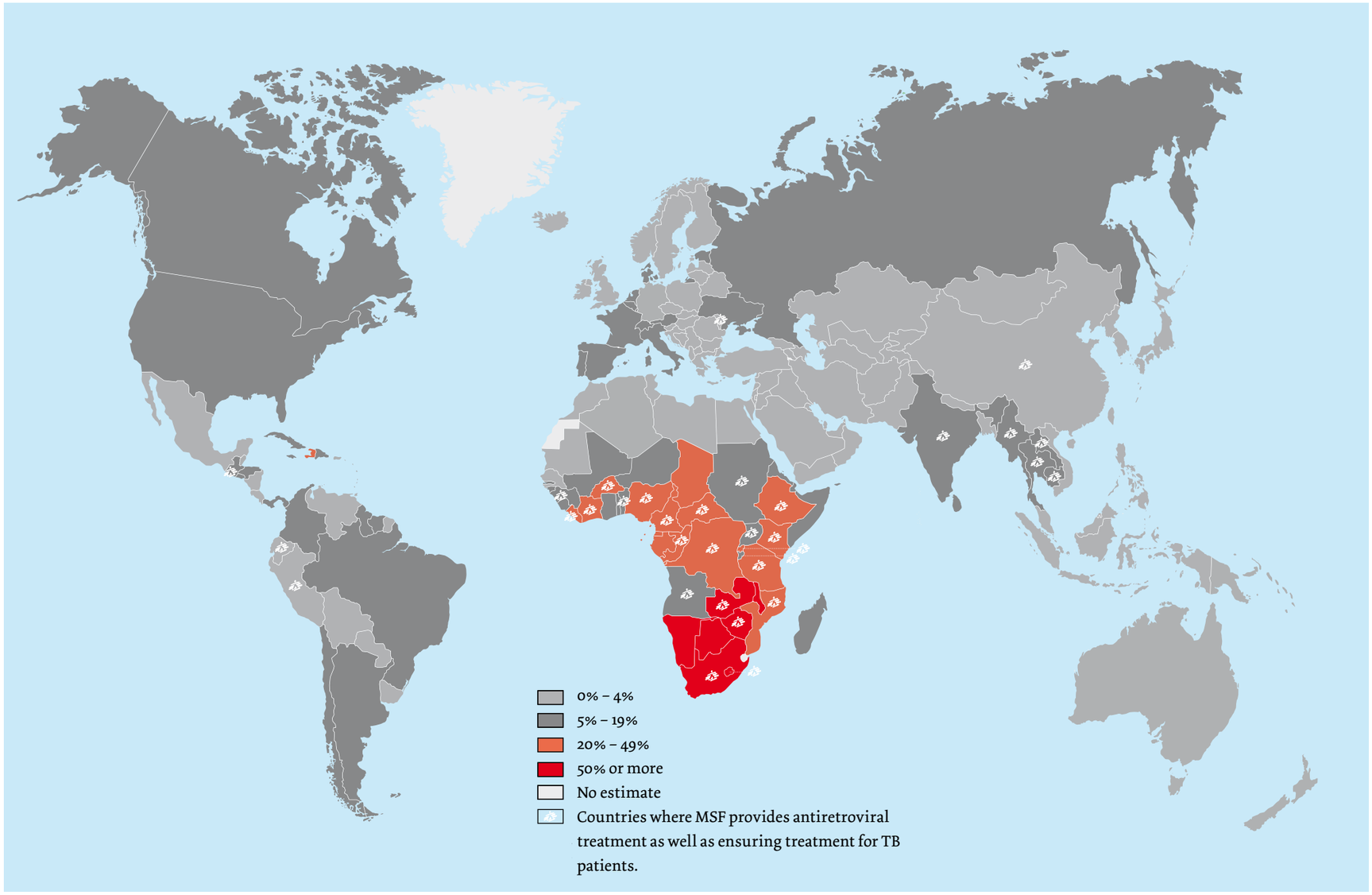
TB AND HIV PROGRAMMES CONTINUE TO WORK IN ISOLATION

The separate worlds of TB and HIV are a huge barrier in tackling these diseases. Most countries have programmes designed specifically to manage TB, focusing on the public health risk of spread of the disease and prevention of resistance to the drugs used. These so-called 'vertical' programmes usually operate quite separately from the rest of the health system.

HIV care, though it has developed much more recently, also developed in a vertical fashion. Unfortunately there has been little cooperation between TB and HIV programmes. Despite clear statements from the World Health Organisation and others on the importance of integration and cooperation very little is changing on the ground. The vast majority of co-infected patients are still failing to access care and TB and HIV programmes continue to work in isolation from each other.

This means that in many programmes where MSF has developed a focus on HIV care there has been a struggle to ensure that patients receive good quality TB care. Lack of funding and focus on TB have left co-infected patients facing a two-tier service: high quality care for HIV providing they can attend the centralised health clinic, and low quality care for TB often available closer to their homes. Those patients with HIV who live far from the nearest hospital will not be able to get care, and TB patients with forms of TB that cannot be diagnosed or treated in the local clinic will also suffer. Increasingly it is clear that the best way to ensure good care for co-infected patients is to provide care for both TB and HIV at the same site – an integrated service.

ESTIMATED HIV PREVALENCE IN NEW ADULT TB CASES
(Figure reproduced from WHO report Global tuberculosis control: Surveillance, planning, financing)



Myanmar

MSF is the largest provider of HIV/AIDS care in Myanmar. In the city of Yangon, MSF staff have started 2,500 HIV-positive patients on antiretroviral treatment. The Myanmar project has also provided medical care to more than 6,000 people with TB.

Photos: Chris de Bode


LOVE

6

LEARNING FROM EXPERIENCE

Treatment of TB or HIV/AIDS is usually organised in vertical systems. Integration of HIV and TB treatment must be a priority. MSF has begun to offer routine HIV testing and counselling for all TB patients and HIV patients are regularly monitored for signs of TB.

6.1 TB AND HIV MUST BE TACKLED TOGETHER

Integration of TB and HIV services must be a priority. There is overlap in terms of who is affected and the approach to diagnosis and treatment, and in terms of the similar needs for monitoring, funding, staffing, community support, nutritional support, drug supply, and training.

"TB systems are usually vertical organized systems. In every town or district you will have a TB system. Next to it there might be another vertical organized system for AIDS. You go for your AIDS infection to the AIDS doctor and for your TB to the TB doctor. This is of course an extra burden for the patient and poor medical practice. In MSF's Myanmar programme we don't have that problem because in our clinic we treat both. There is not an AIDS doctor and a TB doctor. We have a doctor who treats patients whatever you have.

— Dr Frank Smithuis, Head of Mission and Medical Coordinator, Myanmar.

REASONS TO INTEGRATE TB AND HIV PROGRAMMES

- The two diseases often exist in the same person;
- They both require the diagnosis and treatment of the other to achieve the best results from the treatment;
- They both rely on a good drug supply;
- Both treatments must be taken carefully by the patients for a long time;
- If the drugs are not taken daily the patient will not respond well to treatment;
- Poor adherence can lead to drug resistance;
- A huge additional burden is placed on both the patient and the health system if such similar diseases are treated by different people and at different locations

MSF staff involved in the care of HIV patients are trained to look regularly for signs of TB, and programmes have recently begun to offer routine HIV counselling and testing for all TB patients. Where the uptake is low, we attempt to address the barriers to testing. These barriers include:

- Cost (MSF always provides the test free of charge);
- The testing centre being too far away (MSF tries to ensure the test is always available in the same place that the patient is being treated for TB);
- Lack of patient understanding about the reason to take a test (MSF staff take time to explain the benefits of testing).

Wherever testing is offered we try to ensure that full care and support, including ARV treatment, is also available.

MSF also acknowledges that nutritional support is an essential part of treatment and ensures that all patients receive enough to eat along with their supply of drugs. HIV patients starting their treatment on ARVs are provided with balanced food for an initial period of three months. To ensure that patients are using their food rations themselves, their families are provided with support as well.

CASE STUDIES: INTEGRATION MAKES A REAL DIFFERENCE

SOUTH AFRICA

In the MSF project in Lusikisiki, South Africa, where around 66% of TB patients are HIV-positive, integration has made a real difference. In July 2006, after an integrated training, nurse and community carers in eight out of nine primary clinics started to routinely offer HIV testing to TB patients. The proportion of TB patients aware of their HIV status increased from 45% in July 2006 to 75% in September. By contrast, in the one clinic that did not integrate care and where PITC (Provider Initiated Counselling and Testing) was not routine, only 29% of people took an HIV test.

MALAWI

MSF has also tried to decentralise and integrate treatment and follow-up care to increase its acceptance and accessibility. For example, in Malawi, initially only 44 (13%) of 352 TB patients who needed ARVs attended for follow-up and actually received their treatment. This was found to be due to the distance they would have to travel to get ARV treatment. They managed TB treatment because it was delivered from their local clinic, but they could not afford to travel in to town for HIV care. The only way to solve this problem was to provide the HIV care at the local clinic, alongside the TB care.

MSF RESEARCH

MSF is conducting operational research to try to ensure that people in need receive treatment. Old approaches are being assessed and adapted, and new tests and drugs are being applied. We are also pushing for greater international support for research and development of new diagnostic tools and treatments. A few examples of the research being carried out by MSF include:

- Documenting the feasibility and impact of routine TB screening in HIV clinics;
- Rapid field appropriate techniques for TB culture, including techniques such as MGIT (Mycobacteria Growth Indicator Tube);
- Optimising use of old diagnostic techniques (smear, cytology, concentration);
- Monitoring the impact of charging fees on patients' access to and standard of care;
- Implementing and monitoring the impact of integrated approaches to care;
- Evaluating TB and TB/HIV diagnostic algorithms.

6.2 IMPROVING DIAGNOSIS OF TB

Health workers can maximise the chance of making a correct and timely diagnosis by ensuring good quality sputum collection and microscopy. MSF is focusing on improving the routine examination of sputum and the use of concentration methods to increase sample quality.

> *"The instructions given to produce sputum influence the quality of the sputum and therefore influence the outcome of the test. MSF currently runs workshops in the Rural Health Centres (rural clinics) explaining to community health workers how to collect sputum. I think we should continue with these workshops on a regular basis because it is very important to get good samples."*
> **— Jairo Mbewe, Laboratory Technician for MSF, Nchelenge, Zambia.**

In Khayelitsha, South Africa, the use of fluorescent microscopy to diagnose TB of the lung has increased detection rates by 60%. We are also looking at ways of simplifying and speeding up culture for TB for diagnosis and for testing for drug resistance. We are assessing clinical algorithms to diagnose TB in HIV-positive children, which is one of the greatest challenges in providing treatment.

Ultimately, however much the tools are improved, HIV-positive patients will often have TB that cannot be definitively diagnosed. To ensure that these people do not fall through the net, solid clinical skills training is required.

> *"If I see someone sick in my community with symptoms of TB, I tell them to get tested. I never forget to mention that they should get tested for HIV as well. I know how to recognize TB. As a Voluntary Community Worker, I also visit sick patients that have already been tested, just to support them."*
> **— Mwansa, 40 years old, Zambia. He had been co-infected with TB and HIV.**

6.3 COMMUNITY INVOLVEMENT

The lack of trained staff presents a huge barrier to ensuring appropriate services for people with TB and HIV. The problem is especially severe in rural areas and in conflict-affected settings. MSF programmes are seeking to mitigate this problem by shifting tasks to less highly trained health staff and to communities and people living with HIV/AIDS themselves; by providing more training for doctors and nurses; and by ensuring that services are integrated wherever possible to use available staff more efficiently. However, these approaches need to be expanded.
In MSF programmes, people living with HIV are often recruited or volunteer to help educate and care for others with the disease. Those involved with TB or HIV in the community are being trained in the care and support of those with both diseases. They are trained to recognise the signs of both diseases to ensure people come for diagnosis and treatment before it is too late. They help patients adhere to their drug regimen; recognise patients' problems and encourage them to seek health care early; and even provide treatment and care themselves. They have proved invaluable in:

- addressing stigma and increasing awareness to encourage people to test or seek treatment if sick;
- providing friendship, support, and health care to people with HIV/AIDS;
- ensuring that this support is accessible without the need to travel far;
- helping those on treatment to keep taking it properly;
- tracing those who have dropped out of treatment and helping them return to care;
- reducing the burden placed on doctors and nurses in clinics.

VOLUNTEER COMMUNITY WORKER

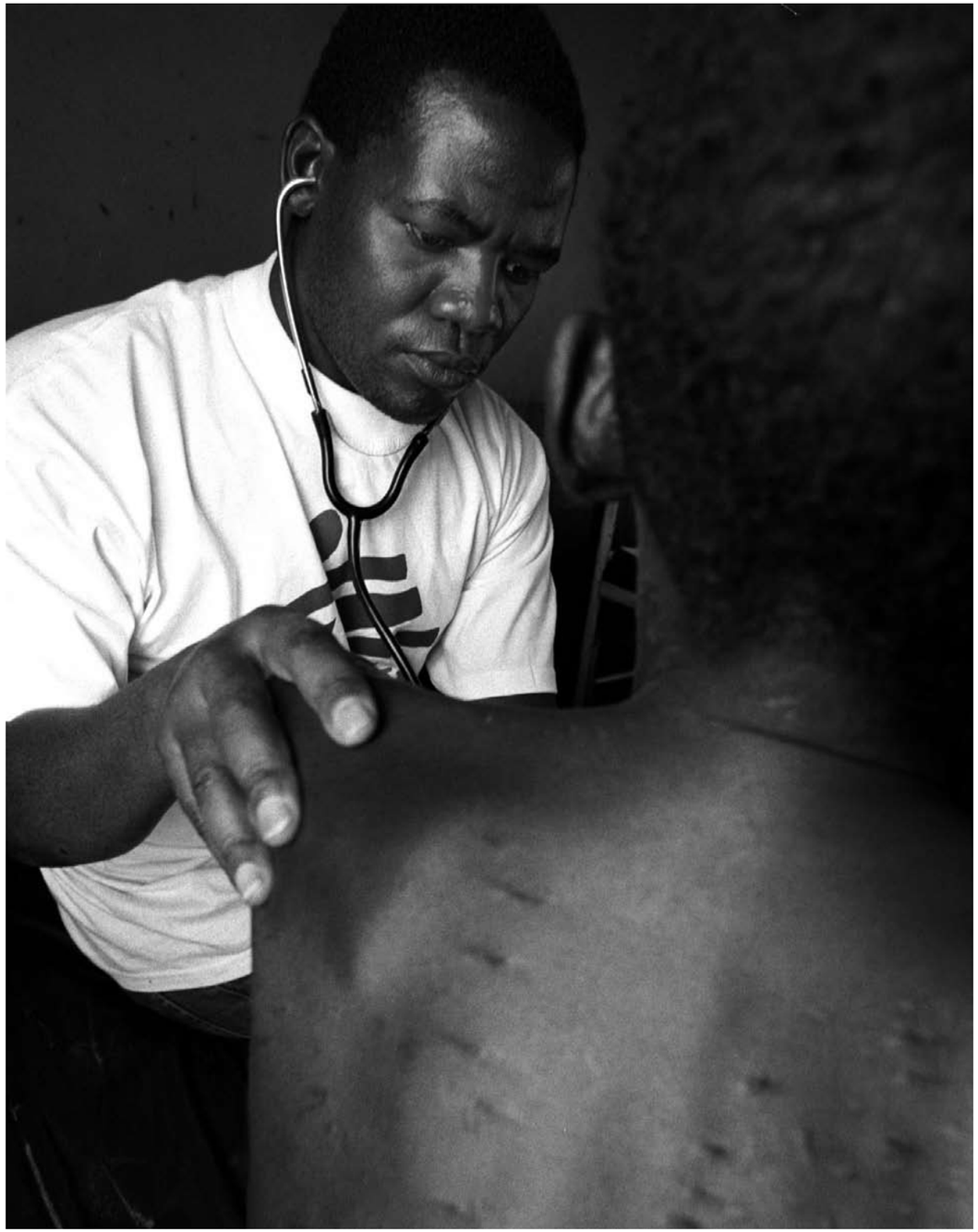
— Masautso, 37 years old, is a Voluntary Community Worker, who helps detect and take care of TB and HIV patients. He had been co-infected with TB and HIV.

"I am fine now. I have had some tough times, but I survived. When I meet other patients that are reluctant to take a TB or HIV test, I always try to convince them. I give myself as an example. I was once also very sick, but now I am as strong as a horse. I would like to say to other co-infected patients that life is worth living, you should get treatment. You only have one life, you should take this opportunity and get some treatment. Without it they will die. And that is completely unnecessary.

Since 2004, every Monday and Friday morning I work as a psycho-social counsellor for HIV patients. I speak to patients who are about to get an HIV test and explain to them what the disease is and that they shouldn't be afraid. After they are tested, and if they are positive, I explain to them what treatments there are.

Since 2005, I have been working as a TB counsellor as well. That means I go into the villages to find sick patients that might be infected with TB. I tell them they should get tested. I send them to the clinic and I take a sputum sample from them to get tested.

As a community worker I also visit the sick that are in bed. And I follow up patients that are taking HIV or TB treatment. All this I do voluntarily. On Tuesday, Wednesday, and Thursday I work as a farmer and try to earn my living with that."



ACTION NOW TO PREVENT MORE NEEDLESS DEATHS

There is a stark contrast between the rhetoric and promises surrounding HIV and TB internationally, and the experiences of our patients and those who care for them. Greater urgency is needed in implementing accessible services for people confronted with this double disease burden.
To combat TB and HIV and stop the rising tide of needless deaths, action in several areas is needed now:

- Routine HIV testing and care must be made available and accessible for all TB patients and vice-versa;
- Shorter (6- rather than 8-month) TB treatment regimens must be used;
- The DOTS policy has been revised, but adapted strategies to cope with the effects of the HIV epidemic need to be implemented on the ground. HIV patients with smear-negative or extra-pulmonary TB must not miss out on treatment;
- Better tools for diagnosing TB are desperately needed, along with drugs that can reduce the length of treatment and pill burden. Increased support for research and development must be made available to meet these goals and ensure that the tools developed are affordable;
- Long-term goals of effective TB and HIV vaccines must be addressed – but should not distract from the immediate and more achievable steps that must be taken now.

Without immediate action, these epidemics will continue to claim the lives of millions of people every year.

FOOTNOTES

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