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AccessNews

CAMPAIGN FOR ACCESS TO ESSENTIAL MEDICINES

MEDECINS SANS FRONTIERES

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The Time is Now

What can you do when tuberculosis is spiralling out of control in Africa, there are no good drugs or tests to treat and detect the disease, and the earliest available solutions can't be expected for another decade? Dr. Tido von Schoen-Angerer, Director of MSF's Access to Essential Medicines Campaign, argues that despite such a bleak outlook something can be done, and it must be done now.

There is no hiding the verdict: we are losing the battle. And South Africa, where the world's biggest tuberculosis conference opens this week, is very much at the frontline. The spread of resistant strains of tuberculosis, coupled with the HIV epidemic in the region, and the overwhelming lack of appropriate tools to tackle the disease all mean Médecins Sans Frontières (MSF) teams are increasingly struggling against odds that cannot be won without radical action.

There are no good tools that can be used in remote settings to detect TB, especially for HIV positive patients; no good tools that can be used in remote settings to detect resistance and thus to determine which drugs should be given to a patient; the first-line regimen is very lengthy and interacts with antiretrovirals; the second-line is a combination of weak and toxic drugs; there is no effective vaccine.

MSF teams in Kenya, Lesotho and beyond are doing all they can now to explore less centralised treatment strategies to treat drug-resistant TB where HIV is so common. But this is not good enough. However much we strive to explore alternative strategies, the bottom line is that we are simply not going to win with the medical tools at our disposal today.

We cannot afford to wait ten or fifteen years, the earliest a whole new line of TB drugs can be expected. We must bring solutions to our patients as soon as possible. With drug-resistance and the HIV/TB co-epidemic raging, sitting back and waiting a decade or two is not an option.

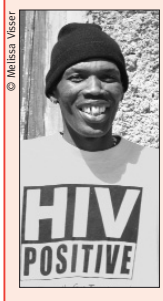
One concrete way to accelerate things is to conduct clinical trials for all new TB drugs in MDR-TB patients. This would help us work out faster which new drugs are effective against drug-resistant TB - precisely where new drugs are needed most desperately. It would also speed up the regulatory process and allow earlier delivery of new drugs to patients with standard TB. Of course, more compounds need to be added to the pipeline - but this is one way to move as fast as we can.

This concept, discussed at a MSF symposium in New York earlier this year, is developed by leading international experts - from Harvard University, the US Food and Drug Administration and the US Centers for Disease Control - in an important publication from the Public Library of Science this very week. One of the TB drugs in clinical development has already started to undergo such a trial in South Africa. But while the company Tibotec is leading the way, the owners of other compounds need to follow suit.

We need to act now, and get moving faster. But we also need to consider the longer-term. As the TB conference opens in Cape Town, Ministers of Health are gathering in Geneva at UN-sponsored talks to negotiate on a global action plan on access to medicines and medical innovation. If successful, this Intergovernmental Working Group could promote a new R&D framework that could bring a boost to R&D for diseases that mostly affect developing countries. Tuberculosis, where such a boost is so urgently needed, will be the litmus test of their success.

Tido von Schoen-Angerer

Positive Voice: How sharing experiences improves treatment and gives hope



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Every day, Joseph Ramokoatsi - an 'HIV/TB lay counsellor' working at St Rodrique health centre, an MSF-supported clinic in the mountains of Lesotho - sees more than 50 patients who have HIV, TB, or both infections at the same time. Joseph counsels patients about the importance of knowing their HIV status, the difficulties they may encounter in the course of their HIV or TB treatment, and the importance of adhering to treatment.

These are all well-known challenges for Joseph. He himself is fighting HIV and has had TB several times. "*I found out I was HIV positive in April last year. I decided to get tested because I had TB, and after finishing the treatment I was still very sick. So I wanted to know my status.*" He has been on ARVs for more than one year and although his immune system is becoming much stronger, he once again has symptoms of active TB.

Lay counsellors like Joseph have helped expand HIV testing and counselling in the area and improve uptake and delivery of HIV services. As nurses take on more clinical responsibilities under the decentralisation of HIV care, lay counsellors have absorbed numerous tasks - not only educating and counselling but also weighing patients, completing patient paperwork, and in some cases performing triage for stable patients - thereby reducing the nurses' workload. The fight against HIV and TB does not diminish Joseph's strength and optimism. He wakes up every morning long before the sun rises to work in his family's fields. At six, he sets off to the clinic, a four-hour walk away. "*I don't feel ill. I only feel I have a problem when I don't do anything that day.*"

Joseph is the face of a "Positive Voices" poster campaign that encourages people to get tested and to access treatment in facilities supported by MSF. "*What I like most about my job is that I give hope to the people. When people see the posters, they don't believe it is me, that I am alive. So when they see me, they are happy and it gives me something to be happy about.*"

Alessandra Vilas Boas

© Alessandra Vilasboas, MSF

'One-Stop Shop': At MSF's integrated clinic in Lesotho, Dr. Pheello Lethola sees patients with both HIV and TB.

Living with two killers: Tackling the twin epidemics of TB and HIV in Lesotho

Lesotho has the third highest adult HIV prevalence in the world, the fourth highest tuberculosis incidence, and an alarming rate of TB-HIV co-infection. Rachel Cohen, head of mission in Lesotho, explains the challenges and constraints as well as the innovative tools and strategies MSF is introducing to try to improve diagnosis and management of TB. MSF works in Scott Hospital Health Service Area (HSA), a rural health district, supporting a 102-bed district hospital and a network of 14 primary health care clinics, many in remote mountain areas.

When we started working in Lesotho in January 2006 we had one main objective: to reduce HIV-related illness and death by bringing HIV/AIDS care and treatment, including antiretroviral therapy (ART), as close as possible to the people who need it, at their nearest clinic.

But we quickly found that our efforts to decentralise HIV care and treatment to the primary health care level were being complicated by an overwhelming 'twin epidemic' of tuberculosis. An analysis carried out by MSF in September 2006 found that 92% of TB patients in Scott Hospital HSA are co-infected with HIV. As a result, we are integrating TB and HIV services to ensure a 'one-stop shop' for co-infected patients, allowing them to receive the medical care and adherence support they need for both diseases at the same time in one place.

We have also reduced the need for patients to travel long distances to hospital for lab investigations by introducing a specimen collection system - a dedicated vehicle that comes to each clinic once a week to pick up samples of sputum, blood, and so on needed for HIV, TB and other conditions and transports them to the district hospital laboratory for analysis.

Despite these efforts, as in other high HIV prevalence settings, TB is still the leading cause of death among our patients in Scott Hospital HSA, and this is often because the diagnosis of TB is delayed or never made at all. The traditional test method is not sensitive enough and works particularly poorly in HIV-positive people. As a result patients' lab results show up as 'smear-negative' even when they have active TB.

To address the challenges of diagnosing TB in our setting, we are introducing a 'bleach concentration method' that has been shown to increase the visibility of TB under a microscope. We will also pilot a new rapid culture technique in the lab, which will provide a faster and more sensitive method to diagnose active TB as well as drug-resistant (DR) TB.

In addition, we have launched a pilot project to train nurses at the primary care level to diagnose

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A long and toxic road to being cured: Living with MDR-TB in Uzbekistan

With 13% of all newly diagnosed tuberculosis patients infected with multi-drug-resistant strains according to a recent MSF study, the Central Asian republic of Uzbekistan has one of the highest rates of MDR-TB in the world. In 2003, in cooperation with the Ministry of Health, Médecins Sans Frontières started treatment of drug-resistant TB in Nukus and Chimbai, in the west of the country.

57 year-old Ismail Kadyrov has recently completed eleven months of TB treatment. For eight of those months he was confined to a hospital bed. This was the second time Ismail had to be admitted. After recovering from a previous infection, he was bed-ridden for a month in a community in-patient ward, waiting for the side-effects from the drugs used to treat him to subside. They left him unable to walk. Then he discovered that his TB infection had reappeared and he had to return to the main hospital.

Ismail's story of hospital confinement is typical. While regular TB can be treated in six to eight months and patients are usually not hospitalised, the resistant TB bacilli of MDR-TB require a much longer bombardment with toxic drugs that are also weaker than the first-line drugs. As a result, treatment lasts between 18 to 24 months, including between two to six months in hospital.

Some patients simply cannot cope with their treatment or the length of their admission. Others start to feel better and decide to stop, or have pressure put on them by relatives to come home from the hospital. Although the project tries to be flexible, and allows people to go home temporarily if their treatment is progressing, some patients don't return and default on their treatment. They then run the risk of developing even greater resistance to TB drugs and infecting those around them.

"The most difficult part was the side-effects caused by the medicines. I had to vomit constantly and saw things that weren't there. Still I never considered stopping treatment. I had to live for my small daughter. It is hard to imagine how happy I am to be cured."

A female patient at the MSF programme in Nukus

Once discharged from hospital, patients still need to come to health centres to take their drugs. They are only deemed to be cured when their sputum culture has repeatedly tested negative for TB. Many find the grind of this outpatient phase also very hard. Although MSF tries to ensure that patients can attend a health post near their home, many still have to travel up to an hour to get to the clinic each day. MSF also offers other support services to help patients and their families.

On top of facing MDR-TB, MSF is also encountering cases of extensively drug-resistant TB (XDR-TB) in Uzbekistan. This form of TB responds to virtually no treatment. By analysing drug sensitivity and resistance in sputum-positive MDR-TB patients in this project over a three year period, MSF found that 7% developed XDR-TB during their MDR-TB treatment.

It is clear that health staff urgently need more tools to improve the treatment options for this debilitating, killer disease.

■ **Emma Bell & Susanne Doettling**

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■ *Nukus, Uzbekistan: A patient holds in her hand a sample of her daily medication.*

"I get terrible headaches, dizziness and loss of appetite. It is better now, but there were times in the past when I just wanted to die, I felt so low and depressed. Maybe it was the drugs, or maybe the length of treatment, but it all just seemed too much."

Sarsenbai Menglibaev, a patient from the Nukus MSF project pictured below with his family.

MSF's Dr Cathy Hewison describes the realities of treating MDR-TB in the breakaway province of Abkhazia, Georgia

"We explain that the treatment is very long, with very violent side-effects and very serious constraints. Those who start this treatment have to know that they will neither be able to work nor sleep with their partner, nor play with their children whilst they are infectious... The intensive phase under hospitalisation lasts a minimum of six months. The patient takes a cocktail of five molecules, which means a painful injection every day and a handful of pills every morning and every afternoon.... Side-effects are not only unpleasant, but are, in fact, often unbearable, and can actually be dangerous.... It is a treatment that is as violent and toxic as cancer chemotherapy."

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Continued from cover: Living with two killers

and initiate treatment for smear-negative TB based on clinical signs and symptoms, rather than just smear results.

But perhaps the most daunting challenge of all is that of treating drug-resistant (DR) TB. As of September 2007, MSF has confirmed MDR-TB in 19% of culture-positive samples processed from suspects in Scott Hospital HSA.

At the national level, Lesotho is making major strides to improve capacity to diagnose and treat DR-TB, with major support from Partners in Health. However it is clear that given the ever-increasing numbers of patients with DR-TB, a more decentralised approach to MDR-TB management must be explored.

Working in partnership with the national TB programme, Partners in Health, and other actors, MSF hopes to pilot decentralised management of MDR patients in Scott Hospital HSA. This is a major challenge given the difficulties of MDR-TB treatment: frequent and severe side-effects, daily injections for six months, an overall duration of treatment that can be up to 24 months, management of co-existing HIV disease, and a high risk of transmission of MDR-TB if good infection control measures are not in place.

The need for innovation in how we manage TB has never been more urgent.

■ **Rachel M. Cohen, head of mission, MSF Lesotho**

Dying for a test:
"We need to break the cycle of neglect"

Martine Usdin, Biologist with the MSF Campaign for Access to Essential Medicines, is organising a seminar on tuberculosis diagnostics R&D at the start of the Cape Town Conference on TB. We ask her what needs to be done for better TB diagnostics, now and in the future.

What are the biggest challenges today in diagnosing TB?

Diagnosing standard TB has always been difficult. But the emergence of drug-resistant strains has considerably complicated the challenges: for patients with drug-resistant strains, it is crucial to identify which drugs work and which don't through drug sensitivity testing or DST. Evidence shows that patients with drug-resistant TB who are treated inadequately with first-line drugs do very much worse than if you treat them with the correct drugs from the start.

Also, TB is the number one killer of HIV patients. But they are often too sick to produce a sputum sample or have the very severe extra-pulmonary forms of TB, which are also harder to diagnose.

Are today's tests suited to these challenges?

No, they are woefully unsuited. Existing tools are very insensitive. Out in the field, smear microscopy will identify less than half the patients that have the pulmonary form of TB disease. Culture, which is more sensitive and can also give DST information, is complicated to perform, requiring expensive equipment that is hard to maintain, and is also slow - it can take weeks to months to get an answer. For patients with HIV and that are infected with resistant TB strains, most of them die before their DST results are available. Modified culture methods are being developed that are simpler and faster. But they are still not simple enough to make them useful in the most remote areas.

What are the critical characteristics needed for a test to be useful in remote settings?

Ideally it shouldn't require electricity or refrigeration. It must give an answer rapidly, within a few days at most. It should give an answer that is easy to interpret, and that can then be used to directly influence the management of patients, for example a positive test means treat or refer to the clinic, and a negative test means no action. It needs to handle large numbers of patients per day. Of course, it must also be affordable.

What are the main obstacles that holding up the development of new tools?

We need more money, and that money should go to different sources. Today, funding for TB diagnostics development is mostly channelled through the product development partnership FIND, which has gathered a powerful team of accomplished minds to help develop products, but has also chosen to focus methods on tests that can be commercialised - a model that has its merits but should not be the only one.

But it doesn't stop at money. We need more research into the fundamental scientific questions that need to be addressed. TB is a hard organism to work with, and scientists find it hard to have some of the fundamental research questions funded.

Also, although they're not great, some helpful improvements in the tools available today are possible. We need more studies to demonstrate whether these tools can make a difference and more implementation in the field of existing and emerging innovative tools.

What needs to happen now?

We need to dare more, to ask for more. Things move so painfully slowly in the TB world, and we don't have the luxury of time any longer. If we had acted boldly 60 years ago, we would be in a very different place now. We need to break this cycle of neglect and hesitation. This is an ethical requirement for our patients. We don't have any time to waste.

Laura McCullagh

For more information on the TB diagnostics seminar at Cape Town see:

http://doctorswithoutborders.org/events/tbcapetown/

Why DR-TB trials need to happen now

The WHO Global Plan for tackling MDR/XDR-TB calls for the treatment of only one tenth of all those expected to contract the diseases over the next ten years. Carole Mitnick, Instructor at Harvard Medical School, says that faced with such bleak figures, innovative approaches to deliver effective new medicines to combat the resistant forms of tuberculosis must be adopted now.

This is the grim reality of the drug-resistant TB epidemic: approximately 1.5 million people will suffer from multidrug-resistant tuberculosis (MDR-TB) this year; one-third will likely die without ever gaining access to appropriate therapy; those fortunate enough to receive treatment will endure 18-24 months of once or twice daily therapy with at least four drugs and face appalling side-effects ranging from severe vomiting and diarrhoea, through to psychiatric and neurological problems. Some will go deaf. One in five will die during this ordeal and those patients who develop further resistance to critical anti-tuberculosis drugs, will have even less chance of survival, especially those co-infected with HIV.

There is a growing consensus that universal access to high quality treatment for all patients with TB, including those infected with drug-resistant strains, is the right of every patient and is sound public health practice. There is now an opportunity to accelerate the process of getting better treatment to people suffering from drug-resistant TB through innovative clinical trials

Such trials have never been undertaken for MDR-TB for many reasons. A prominent concern is that evaluating new drugs for MDR-TB would divert scarce resources from the development of shorter treatment for drug susceptible or standard TB. But the threats of MDR/XDR-TB are key to mobilising increased funding for all TB drug development.

Furthermore, testing new compounds in MDR-TB patients as well as for standard TB is likely to accelerate regulatory approval for new anti-TB drugs. Such has been the experience in HIV where clinical trials in patients with drug-resistant disease have shortened the approval process for new anti-retrovirals.

The process of development will also be speeded up because the anti-TB activity of new drugs will be more easily detected in patients on failing treatment. Trials therefore can be conducted with fewer patients and completed more quickly, while acquiring safety data important for all TB patients.

The benefits will not be confined to patients suffering from drug-resistant TB. If smaller, shorter trials lead to better use of limited trial capacity and faster regulatory approval, the hurdles for all TB drug development will have been substantially reduced.

This way, benefits will accrue to all TB patients and the financial and human toll of drug-resistant TB will be mitigated. In order to hasten the glacial pace of TB drug development, we must seize the opportunity now before us. There is a moral imperative to make new and effective treatments available to the millions suffering with all forms of tuberculosis.

Carole Mitnick

The full arguments for accelerating DR drug trials, set out by Carole Mitnick and co-authors, will be appearing in PLoS Medicine, at www.plosmedicine.org, on 6th November.

Overcoming the gaps in TB research:
Do we need to rewrite the rules?

A six or eight months long treatment course relying on old drugs, a two-year long second-line treatment of expensive, toxic drugs that are difficult to procure and often don't work, the emergence of deadly strains of XDR-TB, the absence of accurate easy-to-use tests to detect infection, let alone drug sensitivity - the list of gaps in tuberculosis research and development can seem terrifyingly daunting.

At a 2007 symposium convened by MSF on tuberculosis drug R&D needs, more than 100 experts from around the world including drug developers, clinical researchers, health professionals, policy makers, donors and activists recognised that "the lack of TB drug development is a result of the failure of the current profit-driven drug research and development model."

Put more simply, that means that to plug the gaps in TB research, you need to rewrite the rules that govern the way essential medical R&D is done today. TB has suffered from decades of neglect from pharmaceutical companies, researchers and policy makers, because with until recently, it offered no lucrative rewards and incentives for investment into R&D.

The participants of the MSF symposium point to talks going on now at the UN for an answer to this problem: "With respect to TB drug development, participants of the New York symposium support current discussion at the WHO for a treaty on essential health R&D that addresses the question of who pays for essential medical R&D and de-links incentives from drug prices, instead rewarding the impact of inventions according to health care outcomes."

Talks organised by the WHO in Geneva this very week, at the same time as the TB conference in Cape Town, will see Ministers of Health from around the world gather to negotiate a plan of action and strategy to address the gaps in essential R&D and access to the medicines, diagnostics and vaccines of today and tomorrow. In other words, how the R&D rules might be re-written so that diseases that disproportionally affect developing countries, (and therefore carry little financial incentives for the pharmaceutical industry to address), can be prioritised.

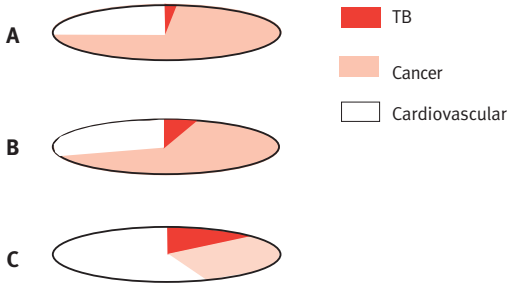
The Intergovernmental Working Group on Public Health, Innovation and Intellectual Property (or IGWG, to give the meeting its proper name), will look at other potential areas of action - such as addressing the funding gap for R&D (the annual shortfall for TB was recently estimated US$800 million a year); coming up with new funding mechanisms such as an international R&D treaty, that provide regular and sustainable financing for R&D; overcoming the lack of access to libraries to screen potential compounds held by pharmaceutical companies for action against tuberculosis or other diseases; improving regulatory processes to approve health technologies for neglected diseases; or managing intellectual property in innovative ways, such as making use of patent pools to facilitate upstream and downstream research as well as to improve access to medicines.

If successful, the IGWG could help bring about an end to the chronic neglect of R&D into diseases that predominantly affect developing countries - research that, so long as access to medicines can also be ensured, would eventually provide solutions for the daunting obstacles faced by doctors to effectively detect and treat tuberculosis today.

James Arkinstall

Read more on the MSF symposium on drug development: http://www.doctorswithoutborders.org/events/TbSymposium

Read more on the Intergovernmental Working Group, including MSF's official submissions: http://www.who.int/phi/about/en/index.html



Comparison of drug pipelines for TB and for "more profitable" diseases in 2006

Graph A represents the number of drugs in clinical stage of development and graph B the number of pharmaceutical and biotech companies involved in drugs development projects for Tuberculosis, Cancer and Cardiovascular diseases. *Source: Pharmaceutical Research and manufacturers of America (PhRMA) Survey*

Graph C represents the worldwide burden of disease in DALY (Disability Adjusted Life Years) for Tuberculosis, cancer and cardiovascular diseases.
Source: WHO

Deadly Duo: The urgent need to integrate TB and HIV care

Tuberculosis is the primary killer of people living with HIV: up to half of all deaths of people with HIV are caused by TB. A patient infected with both diseases can be four times more likely to die during TB treatment than someone being treated for TB alone.

The spread of HIV is fuelling the rapid rise of TB in many regions of the world. There are currently 11 million people 'co-infected' with HIV and TB. MSF doctors in countries with the highest HIV prevalence rates, such as Lesotho and Zimbabwe, find that over 75% of TB patients are also HIV-positive.

Given the much higher risks to patients co-infected with both diseases, the challenges of diagnosis and treatment of this dual epidemic are enormous: in Africa, of all those co-infected with HIV and TB, fewer than 1% are getting the drugs that they desperately need.

"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.

Despite clear statements from the World Health Organization and others of the importance of implementing a joined-up approach and integrating treatment, in most places TB and HIV programmes continue to operate in isolation from each other. Globally, only 14% of the estimated HIV positive TB patients were identified by HIV testing in 2005 and only 0.4% of people living with HIV were screened for TB.

MSF is working to ensure that TB care is available for all our HIV patients and that our TB patients are given access to HIV testing and treatment if needed. But there is still much work to be done in pushing forward the integration of treatment for co-infected patients to save lives.

Diagnostic challenges of TB-HIV co-infection

Diagnosing TB is already difficult in resource-poor settings, but is particularly challenging amongst people infected with HIV who develop forms of TB disease that are especially difficult to diagnose. The result is that many TB cases go undiagnosed or are diagnosed very late - often too late for people to get treatment.

Treating TB/HIV co-infection

Treating patients co-infected with HIV and TB is problematic for various reasons. Some of the drugs used to treat the individual conditions interact negatively with each other, reducing their effectiveness and increasing the risk of side effects. For instance, one of the key TB drugs, rifampicin, reduces levels of the antiretroviral nevirapine in the blood, making it less effective in fighting HIV. 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. For people co-infected with HIV and a drug-resistant form of TB, the daily pill burden can exceed 20.

"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, co-infected with TB and HIV.

What needs to happen:

1. HIV and TB patients should be treated at the same point of care
2. Routine HIV testing and care must be made available for all TB patients
3. All HIV/AIDS patients must have access to early diagnosis and treatment of TB
4. Support for R&D is desperately needed to ensure that better tools for diagnosing and treating TB in HIV and non HIV-infected patients are found

For more information read 'The Failure to Act' on http://www.uk2.msf.org/TBReport

Alessandra Vilaboas talks to Dr. Pheello Lethola, MSF's HIV-TB Doctor in Lesotho, about the challenges she faces in her work.

The TB-HIV co-infection rate in Lesotho is as high as 90%. What are the challenges of treating TB and HIV co-infection?

Both diagnosis and treatment are complicated by co-infection. You may think that the patients don't have TB because they have smear-negative TB, the x-ray doesn't show it and their immune system is already so low that the classical symptoms are masked. But two months after you start the patient on ARVs, they come back very sick. And that is the problem.

If you treat a patient both for HIV and TB there are added side effects and sometimes you can't tell if they are from the TB or from the ARVs. You have to be very careful to make sure your patient understands that both diseases are very important and need to be managed properly.

Are these challenges different when you come across patients infected with MDR-TB and HIV?

The diagnosis of MDR-TB takes longer than for ordinary TB, up to eight weeks. But there is not much difference in diagnosing MDR-TB patients with HIV or without it. In terms of the outcome, the difference is that patients who are HIV-negative tend to do much better on MDR-TB treatment than patients who are HIV-positive. Of the patients that we have diagnosed we have found that the ones that are HIV-negative aren't as sick and even if they are very sick, they pick up very quickly. But the patients who are HIV positive can take a long time to recover and the survival rate is not as good.

In Lesotho, MSF provides integrated HIV and TB care. What are the advantages of such an approach?

It is good to have a one-stop shop, where the patient can come for TB and HIV services in one place. We try hard to ensure that the patient doesn't have two different appointment days. A lot of our patients live very far from the clinics; some have to walk up to six hours to reach us. You don't want them coming one week for TB and the next week for HIV, because they just won't be able to come.

Some of the adherence strategies that are used in the management of HIV are also useful for the management of TB. If we have it all integrated under one service, we are able to incorporate the patient education that is done for HIV into TB management. It has been proven that patients adhere much better to HIV treatment than they do to TB treatment. And that is because in TB treatment, patients are meant to comply with treatment, whereas in HIV treatment the patients are made to adhere to treatment.

And how does adherence differ from compliance?

With adherence you educate your patient, there is commitment from the patient, there is involvement of the patient. You don't just tell them which pills they have to take, which is what is done with compliance: you tell the patient this is what you have to do and the patient often has no clue why. With adherence, for example, you tell the patient what side effects they may expect to encounter and what they should do if side effects occur. And for that reason, because patients are involved and educated, they do much better in terms of adherence. So we want to incorporate that into TB treatment too.

■ **Alessandra Vilas Boas**

"I looked at the calendar and I thought I am not going to make it, I will die before"

© Alessandra Vila Boas, MSF

Busi Beko is from Transkei in South Africa. She is the mother of two children - the youngest, a girl, is now two years old. Busi describes how she was diagnosed with both TB and HIV during pregnancy and the ordeal of discovering that her new baby too was infected with drug-resistant TB.

I was pregnant of my second child. I was sweating a lot at night, having chest pains and feeling feverish. I went to the clinic. They tested me for HIV and I was so shocked when they came back with the result saying I was HIV positive.

The sweat was developing and the pain on the chest was growing. They said I must go back to the clinic again so that I get tested for TB.

Because I didn't have sputum, I signed the consent form so that I could do the X-ray even though I was pregnant. I was getting worse, getting thin and very weak. So they did the X-ray and they said I had TB.

The doctor said that I must take out my baby because I had HIV and TB, I was very weak and I wouldn't be able to make it. I didn't want to do it. So I decided to go to Khayelitsha. There I started the ARV treatment. I was already on TB treatment.

I remember I was so ill. It was October and my baby was due in December. I looked at the calendar and I thought I am not going to make it, I will die before.

In December I delivered my baby. Her name is Othandwayo. It means to be loved. Because I was on PMTCT (Preventing mother-to-child transmission), the baby was HIV-negative. I was so relieved! Then in February when I was supposed to be discharged, the doctors discovered that my TB was resisting. I was so shocked because it was the first time I heard about this MDR.

They discovered that my baby - now three months old - had MDR-TB too. She was admitted to the hospital straight away and then they admitted me too. But I was discharged after three weeks. I was crying because I had to leave my baby alone at the hospital.

My baby was finally discharged on the 1st December, one day before her 1st birthday. And 18 months after my diagnosis, I was discovered to be cured. My baby is well too and she is going to finish her out-patient treatment at the hospital soon. I am very happy and proud of myself.

Busi now works with MSF in Khayelitsha as an MDR-TB counsellor. Her baby girl is due to finish her treatment on 13th November.

■ **Alessandra Vila Boas**