



Challenges . Triumphs . Hope

Patients Stories



MEDECINS SANS FRONTIERES
DOCTORS WITHOUT BORDERS



Patients Stories

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Jeremiah Thwala's story



Tifundvo letimcoka talenzaba:

- † Kutfolakala mahhala kwekwelashwa kwe HIV ne TB kunika umuntu litfuba lelisha lekuphila, njengekukhulisa bantwana bakhe, nalokunye.
- † Kwehluleka kubafunela kwelashwa lokungiko kuba nemphumela wekushiywa emhlabeni ngulabo lesibatsandzako
- † Imitsetfo yetemphilo lecinile (njengekutsi umuntu bekanganikwa emaphilisi ekutsintsibalisa ligciwane leHIV uma emasotja akhe emtimba angakehli aba ngephasi kwa200) kwenta umuntu aphute kakhulu kucala kwelashwa, bese imphilo iba yimbi kakhulu, lokubanga neubanyana bemaphilisi lokukhulu

The Thwala family gathers around the small wireless radio set to listen to the commentary of the first match of the 2010 FIFA World Cup tournament. The excitement in the four-roomed house is so intense, even the neighbours passing by outside can feel it.

Like millions of soccer lovers around the world, the Thwalas have been looking forward to this momentous occasion for some time now. For them, the event is all the more exciting because, for the first time in history, the biggest sporting event in the world is taking place in Africa, in

neighbouring South Africa, to be exact.

The Thwala family lives in Jerusalem, a small rural community in the Shiselweni Region, in the southern part of Swaziland.

Swaziland is a small kingdom sandwiched between South Africa and Mozambique.

For 48 year-old Jeremiah Thwala, the head of this family, the moment is a welcome reprieve from the woes of sickness, which has ravaged him for the past two years or so. He cannot help thinking how close he came to missing this historical event.

As he looks around the excited faces of his three children, two teenage boys and a girl, he can only appreciate the second chance he has been given at life. Access to anti-retroviral drugs and drug resistant tuberculosis (MDR TB) treatment drugs has allowed him to get his life back. Jeremiah is one of thousands of Swazis who are co-infected with HIV and TB (in his case, the much harder to treat and deadlier MDR TB).

“ARVs and TB drugs have given me a second chance at life, but it is a pity that my wife did not get this second chance,” he laments.

Jeremiah's wife, Patricia Masuku, died in 2005 before a diagnosis could be made. This was because the family never sought hospital help, believing she had been bewitched.

While many have died needlessly because of such misguided beliefs, yet many more are living because they now have access to free HIV and TB (including drug resistant (DR) TB) drugs from the public health facilities.

Born on the 2nd February 1962 at Ntshanini in Shiselweni, Jeremiah started his primary education at Ntshanini Primary School in 1971 at the age of nine years. In 1977, following numerous seizure attacks, his family decided to move him to New Haven Primary School (now Velebantfu Primary) because they thought he was possessed by demonic spirits (tilwane). It was only later that it was discovered that he was actually epileptic.

While doing his Form Two, he met a beautiful girl,



Jeremiah Thwala's story... continued

named Patricia S'thembile Masuku, who was doing Grade Seven. He instantly fell in love.

In 1984, while Patricia was doing Form 1 and Jeremiah in Form 3, they had their first child. This forced Jeremiah to quit school the following year and go search for a job in the gold mines in Johannesburg, South Africa to support his child and his whole family.

Following a family conflict with his siblings some years later, Jeremiah decided to move his children and their mother, Patricia, who was now his wife, far from his home. He found land in Jerusalem and started building his home there in 2002.

Shortly after their arrival, their youngest child died. Like many traditionally raised Swazis, suspicions of witchcraft were prominent in their minds. Three years later, Jeremiah's wife also died after a long illness. She had been taken to various traditional healers, with no improvement, until she eventually passed away.

Around the same time, Jeremiah also fell ill. While working in Johannesburg, Jeremiah had undergone 6 months of TB treatment. A clinic had been set up at the gate of the workers' hostels, where TB patients would receive their treatment under direct observation of the nurse. However, on holidays and weekends, Jeremiah says the clinic would be closed and, therefore, they would not receive their treatment on such days.

Back home in Swaziland, Jeremiah started having the same symptoms he had had before his TB treatment in Johannesburg. He went to the Hlathikhulu Government Hospital for screening on

three different occasions, but they could see nothing.

"In 2006, I eventually went to Good Shepherd Hospital in the Lubombo Region and there they discovered that I had TB again," he says.

He was put on injective treatment for two months with pills, before he was transferred to Hlathikhulu hospital to continue with his treatment.

When no improvement was seen after this period, sputum was collected from Jeremiah and taken to Mbabane for testing. A month later he was started on treatment for MDR TB. He had to be admitted for the period of six months for the injection phase because patients could not access pills or injections for TB at the clinics closer to their homes. Jeremiah says this was the most difficult time for him because he had to see people in the same ward with him dying and being replaced by others. Two of his friend, with whom he shared the TB ward, lost their hearing, something that scared him a lot. When he also started losing his hearing on the right ear after one month on the injective treatment, he quickly informed the doctor. The doctor explained to him that he would reduce his injection dosage, something that he says helped because he regained his hearing and never lost it again.

Despite all this care and treatment, Jeremiah's condition did not improve. He now had to use a wheelchair to go to the toilet or move around. His waist and spinal cord seemed to have given up, thus rendering his legs useless.

"I then asked that they check everything, including





Jeremiah Thwala's story... continued

conducting an HIV test, because I had learned that HIV often goes together with TB," he says.

Jeremiah says that when he was told he was HIV positive, he was ready to accept his status because he had mentally prepared himself for such. He asked the doctor and the nurses to do everything required to help him get better. He was now also prepared to do his part.

A CD4 count was done and when the result came back as 210, the doctor told him he would not be started on treatment. He said he could only be started on treatment if his CD4 count was below 200.

"I cried and pleaded with the doctor to give me ARVs, but he refused and only eventually agreed to do so after three months, when my CD4 count was at 189," he elaborates.

In November 2007 Jeremiah completed his injective treatment and was discharged. He says one of his ward friends would often refuse to take the pills administered and purposely vomited them every time. A week after he was also discharged on completing the injection phase, the man died. Jeremiah says this taught him that it was not true that one would definitely die once they had MDR TB and started treatment, the problem lies in individuals. He feels that delayed treatment and failure to adhere to treatment are the main factors.

He has seen promising improvement in his health due to perseverance and determination to live. He has come from a wheelchair, to walking with the aid of a stick, to walking completely unaided.

Despite all this, MSF doctor, Hermann Reuter, was concerned with the slow improvement of Jeremiah's condition, yet the TB bacterium was no longer present in his sputum. He then commissioned some tests and Jeremiah was sent to South African specialists. There, it was discovered that Jeremiah's problem was no longer TB, but one of his lungs was extensively damaged. Doctors believe working underground in the gold

mines, where he worked for 21 years, inhaling dangerous emissions, is responsible for the irreparable damage to his lungs.

Jeremiah appeals for more education on TB in the country, saying personally, he is playing his part by educating people wherever he goes, even on buses. He also believes the government should assist patients on long and arduous treatment, which takes away their source of livelihood, with food and transport to and from health facilities.

He thanks MSF for providing transport fares to MDR TB patients in Shiselweni, something that he believes has saved many lives.





Khanyisile Msibi's story



Highlights:

- † Facing denial and anger at being suspected of being HIV positive
- † Fear of stigmatisation leads to late testing and severe health deterioration
- † Joining support group results in acceptance of HIV status, leading to disclosure, acceptance and support from family
- † Dealing with community ridicule and discrimination leads to acceptance of own HIV status and public disclosure, ensuring acceptance by previously discriminately community
- † Treatment adherence leads to regained good health, with a strengthened immune system

After being sick for a long time without seeking help, she became a laughing stock in her community. She was openly ridiculed by some, while others did so behind her back.

Today, 51 year-old Khanyisile Msibi is, like her name, a shining light to many in her family and community.

“The fear of getting tested for HIV and discovering

why I was so sick only resulted in many, many months of suffering, which I could have avoided,” she says.

Born at Shiselweni 2, Embangweni, on the 22nd April 1959, Khanyisile started school at the age of nine years. The reason for her late start was that she lived with her grandmother, who did not have the financial means to send her to school. Her mother lived in South Africa and she never knew her father.

In 1975, at the age of 16 years, she dropped out of school when she fell pregnant with her first child. The child's father denied paternity, so she had to raise this child on her own. To survive, she started selling clothes, which she bought from Durban, in neighbouring KwaZulu Natal province of South Africa.

Six years later, in 1981, she had her second child from her new partner, a man who worked at one of the local banking institutions. Unfortunately, her child's father passed away when her child was only two years old.

History was to repeat itself 12 years later, when the father of her third born also died when their child was only two years old. By this time, she was working for one of Hlathikhulu's oldest hotels, Assegai Hotel, which allowed her to support her three children. With misfortune seeming to follow her everywhere, Khanyisile lost her job in 1998, after 13 years of service, when her boss died and the hotel closed down.

After this, Khanyisile went back home to Embangweni, where she and her children survived mainly on her brother's support. She also took odd jobs here and there, working as a temporal relief in shops, etc.

In 2004, Khanyisile says she started feeling unwell, without necessarily knowing what was wrong with her. She noticed that her facial complexion was getting darker. Her nieces bought her expensive creams, trying to ensure that their aunt continued to look her usual lovely self, with no success.



Khanyisile Msibi's story...continued



Soon after, she started getting severe stomach aches, sometimes even vomiting and passing out. She was in and out of hospital, with her condition deteriorating. She was now also suffering from severe migraines and a doctor advised her to think about testing for HIV.

"I got very angry at the fact that he thought I might have HIV and, when outside, angrily tore my patient cards and left," she remembers.

However, the headaches did not stop. She was constantly in pain and, one day, she woke up with swollen eyes and had to use ice to bring down the swelling. She says she became very afraid because she realised she was going to die and leave her children orphaned. She then wrote a letter, stating who should take care of her children and also asking that they be treated with love. She kept this letter under her pillow, where, if she passed away, it would be easily found.

In all this, she still ran away from the dreaded HIV test "that irritating doctor" had advised her to take.

Her condition continued to deteriorate. One morning she woke up to find the right side of her face dead, with the eye popping out. Her uncle, who suspected that she was possessed by witchcraft spirits, decided that they should seek help from a traditional healer. He asked his wife to

look after her and take her to the healer. Wonder of wonders! The traditional healer told her that her uncle was responsible for her illness, saying he was the one who had bewitched her.

"That was it for me! I got very angry at the traditional healer and that was the day I decided I would go for the HIV test," she says.

The following morning, the 20th June 2005, she asked for money to go for the HIV test. She felt she was finally ready for the counselling and testing session. Her results came back positive and her CD4 count was at 189. The doctor advised her to think about the lifelong, but lifesaving, antiretroviral treatment (ART). She was ready!

After about a month of pre-ART counselling, she started treatment on the 22nd July 2005. She informed her family about her status and says they all accepted and supported her. However, the community members were not so accepting. Many would pointedly make ridiculing comments about her weight loss and the fact that they suspected that she was dying from HIV. Some would then laugh aloud, making sure she heard them. Others would whisper behind her back, looking ashamedly away when she caught them whispering and looking at her.

"Thanks to the help of one nurse here at Nhlanguano Health Centre, Delisile Magongo, who



Khanyisile Msibi's...continued

counselled me and encouraged me to join a support group. Khanyisile joined Sambulo Semphilo Yetfu Support Group, which is under the Swaziland National Network of People Living with HIV & AIDS (SWANNEPHA). She later started attending workshops organised by SWANNEPHA and was surprised to find educated people, like teachers, police officers and others also living with HIV.

"I realised I was not alone and decided to volunteer my services to go to prisons and schools around Nhlangano, where I encouraged abstinence and condom use for those who have already started having sex," she elaborates.

She found that, once she accepted her status and openly talked about it, those who had ridiculed her were disappointed. They no longer had anything to whisper about because it was all out in the open.

Khanyisile says her own acceptance of her HIV status helped ensure acceptance from her community. Today many call on her whenever someone in the community is sick. Sadly, most of those who ridiculed her have died from symptoms she believes are related to HIV. They were too ashamed to seek help because they are the ones who were ridiculing other people living with HIV.

Khanyisile's current CD4 count stands at 789 and it is plain for all to see that she is healthy. She says the key to better health is accepting one's status and faithfully sticking to one's treatment.

She now works as an expert client under the Ministry of Health, based at the Nhlangano Health Centre. Khanyisile's job is exactly about encouraging others to adhere to their treatment. As a person also living with HIV, she is in a better position to counsel others and encourage them that HIV is not the end of the world.

Her advice to others is that all people should stand up early and get tested for HIV, so they can know their status.

She implores, "Sick or not sick, it's important to know your status. Do not wait until you are

bedridden, wearing adult disposable nappies and getting ridiculed."

She adds that testing for HIV does not always mean you will test positive. Khanyisile believes that whatever a person's results, people should feel encouraged to live life in a better, more positive way. That way, they avoid getting infected, if negative, or further re-infected or spread HIV to others, if positive. It is the responsible thing to do!





Lindo Mamba's story

Part 2-My Personal Experience with this wonderful little girl



With this Patient Stories Newsletter being the second one I have worked on, the first having been published in September last year, 2009, I have to say the experience has, at times, been gruellingly emotional for me.

On the other hand, talking to most of these patients has given me hope that my country, Swaziland, may still have a chance to match, pound for pound, the HIV/AIDS and TB epidemics, which have continued to wreak havoc in our communities. Of course, that is if donor governments and organisations stay committed to their pledges to assist low and middle income countries, like Swaziland, in the fight against TB and HIV. It also depends on how committed our own government is to kicking these pandemics out of this country.

In all these stories that I have collected and compiled, one remains indelibly etched in my heart and my mind; the story of little Lindokuhle Mamba.

Despite her petit frame and young age, 7 year-old Lindo has put up an amazingly brave fight against a potentially deadly strain of tuberculosis, the multi-drug resistant (MDR) TB.

The first time I met her, I was dazzled by her beautiful constant smile. Despite ill health, painful injections and the loads of bitter pills she had to endure every day, Lindo just couldn't stop smiling. Her zest for life and the obvious joy and love she displayed for "the aunties and uncles" she met everyday at the TB clinic was nothing, but contagious. She gave one no time to feel sorry for

her. She was just too bubbly for that. Instead she ignited a light of hope in me, this in spite of all the sickly people I had seen earlier on, whose physical, economic and social conditions had left me extremely depressed.

This is the reason I couldn't help but do a follow up on Lindo's condition this time around. I just had to know how she was doing. Had she completed the injection phase of her MDR TB treatment? Was she now in school? Did she still have that contagiously angelic smile?

I was not to be disappointed. This time, I met Lindo at the MSF office premises in Nhlangano, where she was accompanied by her mother. With the same bright smile already widely spread across her face, she said, "Hello auntie!" I was overjoyed to see that she was still as bubbly as ever. Obviously, the MDR TB treatment was having a positive impact on her life.

I learnt that Lindo had completed the injection phase of her treatment in April 2010 after 12 months of having had to endure daily painful injections. She is now only continuing with TB treatment tablets, which she will have to take for some months, until she is discharged by a doctor from the treatment.

"I am happy to have finished the injections, it was very painful", she tells me as a matter of fact.

She is now also attending pre-school at Machobeni, a small community in Shiselweni, and will be starting first grade next year, 2011.

Her grandmother, Thab'sile Macu, who is also the little girl's caretaker, says she is very happy with Lindo's progress. She is determined to see her granddaughter start first grade next year (2011), however, money is a challenge for the family.

"It is really a struggle because we live quite far from the nearest primary school and will need to pay transport costs everyday, something I cannot afford," explains Thab'sile.

Despite these challenges, Thab'sile is determined to do all she can to ensure a bright future for her grandchild.



Mary Lukhele's story



Highlights:

- ↑ Fear of stigmatisation, resulting in delayed treatment
- ↑ Lack of support from partner/ people closest to her
- ↑ Perseverance and determination to live and treatment adherence, resulting in being completely cured of MDR TB
- ↑ MDR TB is also curable, even with HIV co-infection

She is so full of life; one finds it difficult to believe the hardships this lady has experienced, including coming close to death, as a result of HIV and multi-drug resistant tuberculosis (MDR TB).

Mary Lukhele is a 38 year-old mother of **five**, whose life has been riddled with many challenges from a very young age. However, it seems like her life is looking up these days.

She could not believe her ears when she was recently told by a doctor at the TB clinic in

Nhlangano that she was completely cured of MDR TB.

Hers is a story of hope, especially to those who think MDR TB cannot be cured, as well as those who think the treatment is too difficult to adhere to.

“People should not listen to people who say negative things about TB treatment and ARVs (antiretrovirals), yet they have never even personally tried the treatment,” says Mary.

She says, while TB treatment is, admittedly, difficult, MDR TB treatment even more so, positive results are possible through treatment adherence. Mary is a living testimony that TB treatment works because she was cured of MDR TB, even though she is also co-infected with HIV.

“Listening to the wrong advice can make you crazy, so my advice is that people should only listen to their nurses and doctors and nobody else,” she says.

This is exactly what she did and the fruits of that are evident. However, Mary admits that, at first, it was



Mary Lukhele's story... continued

very difficult for her to even think about the possibility that she might be HIV positive or have TB.

Back in the day, as a child living with her mother at eSibovu, a community in Mankayane, where her mother was married to another man, she found herself living a very difficult life. Realising that her daughter was not well accepted by her new in-laws, her mother took her to live with family friends in Manzini. She was enrolled at Manzini Central Primary School for Grade 3 and stayed there until she completed primary school.

"Life in Manzini was also very difficult for me because I was made to feel like an outcast and it was clear that there was no love for me there," Mary says.

She says she would be told to cook food with meat for the family, but would often be told to cook cabbage for herself because "the meat was only sufficient for the owner of the house and her children". This kind of treatment made her decide to rather leave school at the age of 13 and find a job to sustain herself.

She says her first job was with a wonderful lady who worked for Barclays Bank, where, for the first time, she was treated in a humane way.

Having the financial means to live her life as she pleased at such a young age was to have its negative side. By the age of 15, Mary had her first child from a relationship with a Swazi man who worked in the gold mines in Johannesburg, in neighbouring South Africa. The relationship soon ended when she discovered that the man was cheating on her.

She then became involved with another mine worker and had another child with him. In 1999, her lover was killed in the mines in one of many tragic underground accidents that happened there.

In 2000, she met yet another man, with whom she later had two children with, now aged six and four years.



During the pregnancy of her last child, she started feeling sick. She gave birth on the 6th of October 2005. Unfortunately, because she did not take an HIV test during her pregnancy, she could not ensure prevention of mother to child transmission. Her little girl was born HIV positive. Mary says her daughter's CD4 count is currently quite high, so she has not started antiretroviral treatments. She is, however, on Bactrim as a prophylaxis to prevent early deterioration of her immune system and attacks by HIV opportunistic infections.

After the birth of her last child, Mary's condition continued to deteriorate. In 2008, her condition took a turn for the worse. She felt weak at the knees and could not walk and remained in this situation the whole of 2008.

"When my boyfriend realised that I was deteriorating, he changed and started playing games," she elaborates.

Mary says, although she lived with her partner at a small semi-urban location called Holneck in Nhlanguano, he did not take much care of her. She says whenever she asked for money to go to hospital he would tell her that he did not owe her anything.

In the meantime, Mary's health was rapidly deteriorating. She had an endless cough, which was often accompanied by blood. She was sweating at night, suffered from chills and fever and her weight had dropped from a range of 70



Mary Lukhele's story... continued

75kg to 28kg.

"I was basically a skeleton and was close to death's door, and probably would have died, had it not been for the intervention of an aunt to my former partner, who came and took me to hospital," Mary explains.

The lady, whose nephew had two children with Mary, took her to Nhlanguano Health Centre where she was given two sputum specimen bottles. The following day she took back the bottles with sputum specimens from the previous night and that morning. The very same day, she was informed that she had TB and needed to start treatment as soon as possible.

The next day she was enrolled for TB treatment and was advised to also take an HIV test. She decided to ignore this advice, but continued taking her TB medication. After three months of no improvement in her condition, she eventually decided to seek help from another health facility.

Her main worry was that she had failed to take the Nhlanguano Health Centre's advice to take an HIV test.

"I was very scared to do this but eventually decided to go for the HIV test at Tfokotani, a small clinic in another community towards Mahamba, far from where people knew me," she says.

The HIV results came back positive and nurses at the clinic advised her to start antiretroviral treatment, saying her condition would improve quickly if she did so. Mary was so afraid of the stigmatisation that goes with HIV that she decided to, once again, ignore the health workers' advice.

It took the realisation that she would surely die to convince her to go back to Nhlanguano Health Centre and seek help. Nine months after being diagnosed with ordinary TB, Mary was eventually diagnosed with multi drug resistant (MDR) TB. She was told that she would have to start taking daily injections as part of her treatment regimen.





Mary Lukhele's story... continued

"I cried because I worried about where I would get money to travel to the health centre every day," she remembers.

Holneck, where Mary lives, is a 20 minute drive from the health centre. Her legs ached, she was weak and had lost a lot of weight, the injections were painful, her whole body itched and she basically ached all over.

This was the start of Mary's long and arduous journey on MDR TB treatment. She was on daily injections for nine months, getting discharged from this intensive phase of the treatment on the 23rd October 2009. This was the same day she started her antiretroviral treatment. Whatever side effects she suffered she would report to the nurses to ensure they were not fatal. In most cases the side effects subsided of their own accord.

She continued taking her MDR TB pills religiously every day, together with her antiretrovirals (ARVs). This despite some misguided advice from individuals who claimed to know better about ART and TB treatment drugs. She had heard all sorts of scary stories, including that the pills would eat away at her brain and make her crazy. She says she can now testify that all this is untrue.

In May 2010, Mary was given a clean slate by her TB doctor. She has been completely cured of MDR TB. She is now only continuing with the lifelong antiretroviral treatment. She is back to her former self, with a current weight of 76.3kg. Her CD4 count has risen from 182 to 298.

She also says her relationship with her partner has improved and he is now ready to go for an HIV test too, after seeing her condition improve. She is also grateful for the acceptance and support of her mother, who encouraged her to stick to her treatments, saying she would get better.

Get better, she, indeed, has! In fact, she feels strong enough to work and is eager to find a job, especially now that she does not have to go to the healthcare facility everyday for MDR TB injections. Her hope in life is back.





N. Mhlanga's story- A patient's perspective

Young, unmarried mothers know best. The first time you suspect it has happened, you run to the doctor for a test. The mind boggling question is, "What if?"

Still you go for the test and a few minutes later the doctor comes out, white paper in hand, he smiles unsurely...

"Congratulations! You... are going to be... a new mother," he stammers in a tone indicating that he is reading your troubled mind.

Surely, as a mother-to-be, you already have an idea of what comes with these news; change of diet, losing the figure you have all along been proud of in a few months, the curious looks once the symptoms become glaring, you name it. Oh!...and your relationships, especially with "the man of your dreams".

This is exactly how I felt when I was told to go for a TB test. We all know what TB is seen as nowadays. Some call it HIV's best friend, HIV in its window period, the first stop to your grave, etc. But, what was I supposed to do? The TB symptoms were there. I had been on flu treatment for a month,

with no improvement. I was coughing violently, sweated like a stallion both day and night, breathed heavily and was very weak. I had lost a noticeable amount of kilograms...the rest is for you to conclude.

Acting on the doctor's advice and my own conclusions, of course, I went to the Manzini TB Clinic for a test. Two days later, the results came out and I was diagnosed with TB. The nurses enrolled me on TB treatment. They assured me, amidst worried smiles, that I would be fine.

One nurse, a certain Simelane, then led me to a separate room. She measured my weight, which had gone down from 90kg to 75kg. She then explained, in detail, how I was to take the medication. If my memory serves me right, it was six tablets, which I had to take at the same time, once a day. She also gave me supplements such as Folic Acid, Multivite, Pyrodixine, FeSO₄, etc.

I was advised to turn up for check-ups, at least, every three weeks, where tests would be done on my sputum to determine if the medication was working. Treatment was to take, at least, six





N. Mhlanga's story...continued

months. The nurse explained that if no improvement was detected after two months, then I would be put on a new line of treatment.

I dedicated myself to fighting this killer disease. I did everything to the letter, regardless of the side effects. A few days after starting treatment, I lost appetite, became even weaker, all the limbs in my body became stiff. Standing up, sitting down, walking ...it was all a nightmare! My skin was itching. When I complained about this, the nurses told me to be patient and assured me that I was going to adjust. I am not sure if I did, but I faithfully continued taking my medication as advised.

When monthly sputum tests showed no improvement, on the third month I was told to take a culture and drug sensitivity test (DST). I had started treatment in April 2008. It was explained to me that the DST would help determine the kind of treatment I was to be given, based on which drugs

the TB I had was resistant to. Meanwhile, I was to continue taking first line TB treatment.

The DST results came back at the end of August 2008, and I was diagnosed with multi-drug resistant (MDR) TB. A doctor admitted me into a new line of treatment. She prescribed Kanamycin, an injection I would have to take for, at least, six months. She explained that I would have to take tablets for a period of about two years.

The nurse who opened my MDR TB treatment file asked me to choose a clinic I would prefer to take my medication from. This was necessary because I would have to go to the clinic on a daily basis for the injections. I decided to go to Nhlanguano Health Centre. My parents live in Nhlanguano and this would help me cut on transport expenses. I was still expected to take monthly sputum tests seeing that MDR TB is very dangerous and highly contagious.





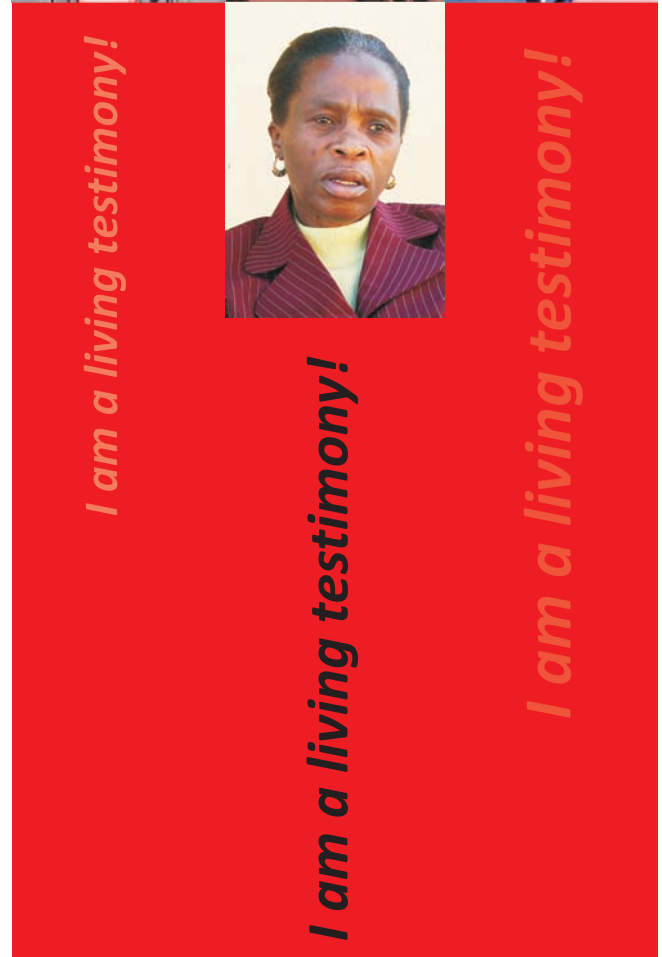
N. Mhlanga's story...continued

In September 2008, I started MDR TB treatment. I must say, the side effects became worse, at times unbearable. I lost my hearing, which I still haven't regained. I completely lost my appetite and, if I forced myself to eat, would throw it all up 90% of the time. My limbs became loose: I could not walk, sit or stand up and needed support to do all these things. My eyesight became very poor and I lost even more weight. I now weighed a scary 43kg. When I consulted the doctors, they insisted that I continue taking my treatment because if I stopped I would die. They were quick to assure me I would adjust, so I persevered.

Months later, I am still on treatment and will only stop when doctors are satisfied that I am fine. I have to say, though the journey is long and torrid, it is probably worth it. I am now feeling a lot better: I rarely cough, can walk, cook, dance a little bit, my eyesight is improving and my appetite is getting better by the day. I have regained most of my weight.

I sincerely thank God for His ever flowing love. I also thank Him for blessing me with an ever supportive team; my families, my church, colleagues, friends, doctors, nurses and students. Without all these people and their support, I would have long taken the nearest route to the grave. I thank all of them for not only listening to God, but for not giving up on me.

To all of you out there, my advice is, as soon as you detect TB symptoms, go for a screen. The earlier the better! As they say, procrastination is the thief of time. Also try to keep yourself informed; read all the material you get on the disease and follow the health workers' advice. Read the Lusweti magazines, they are informative. Last but not least, do not forget to pray to God all the time. He is faithful. ***I am a living testimony!***





Themba Nkambule's story



Highlights:

- † Denial and anger on discovering HIV status
- † Delayed treatment leading to near death
- † Importance of treatment adherence, despite related severe side effects
- † Changing outlook on life to live positively with HIV
- † Religion should not affect treatment adherence

When Themba Nkambule tested HIV positive in 2007, denial and anger made him ignore the results. He continued living recklessly, sleeping with women unprotected, smoking and imbibing alcohol.

Three years later, this kind of life caught up with him, when he got so critically sick he almost died needlessly, at the productive age of 30. Early this year, 2010, Themba, who had been sick on and off since 2007, became critical.

"I had fever, a severe headache and stomach ache, my whole body was sore and my weight had dropped down from 65kg to 50 kg," elaborates the

young man.

A doctor, who had treated him on various occasions and had even advised him to take an HIV test, got very angry when he saw how critically ill he was. He told him that if he wanted to live, he had to take the test. Realising how close he was to death's door, he agreed to do the test. As he had been told before, the results came back positive. A CD4 count was conducted and results came back as 168. After pre-art counselling, Themba started antiretroviral treatment (ART) in January 2010.

"The side effects were very severe and, at some point, I just wanted to

give up," he says.

He says he often threw up every time he took the pills. The doctor advised him to always take the pill again if he had vomited within 30 minutes of taking it. He was also given pills for appetite. Slowly his condition improved. His appetite got better and his weight went up to 63kg. His current CD4 count is 474 and he is feeling very well and healthy.

"The doctor advised me to stick to my treatment faithfully, so I never miss a day of my medication," he explains.

Themba's life, in general, has also changed from what it used to be. He says finding himself without parental guidance at the critical pre-teenage stage had led him astray.

Themba was born at Nkungwini area in Shiselweni, where he lived with his maternal grandmother. At the age of six, he started school at Jericho Primary, where his grandmother was also teaching. When his grandmother got pensioned while he was in Standard Two, he could not continue with school the following year.

A few years later, at the age of 11, he got a job herding cattle at a homestead in a place called



Themba Nkambule's story...continued

Thunzini. During his two year stint as a herdboys, Themba lived his life as he pleased, with no parental guidance. It was then that he started smoking and drinking alcohol.

Two years later, he went to live with his mother and stepfather, but continued living the life he had become accustomed to. Doing odd jobs like washing cars and carrying shoppers and travellers' luggage fuelled his habits as he always had money to buy cigarettes and alcohol.

He was temporarily saved from this destructive life by his uncle's intervention. His mother's brother took him under his wing and put him back in school. Although he had dropped out in Grade 4, he was allowed to start school in Grade 6 at Manzini Central because he seemed quite intelligent.

Indeed, Themba's performance was impressive, at first, and he managed to go all the way up to Form Five, which he completed in 2000. This was the same year he also had his first sexual encounter, unprotected.

When the GCE O'level (Form Five) results came out, his were not good. He believes the fact that he had been unable to give up his bad habits and had become even more unruly, even though he was in school, contributed to his poor performance. As a result of this, Themba could not proceed to college or university.

He spent the next two years staying with his uncle, who now lived in Mbabane. In 2002, he went back to Nhlanguano, where he got a three-month contract job with Hos Textile Company, sewing denim jeans.

After this, he spent about a year unemployed, which he mainly spent back in Mbabane at his uncle's home. Between 2003 and 2004 he worked on a temporal basis for Spar Supermarket in Mbabane. In 2006 he was employed by another textile company, Zheng Yong, where he worked until 2008. This was when he and others got fired for stealing some denim jeans.

Being unemployed once again plunged him into a reckless life, filled with woman, alcohol and cigarettes. In the meantime, he was frequently sick, on and off, something that had started back in 2007. His main problems were headaches and severe stomach problems. He probably had ulcers, he reasoned with himself.

At some point, he spent two months at Nkhungwini area, where, he says, he started reasoning with himself, questioning the direction of his life. He realised that continuing like this was leading him down the road of destruction.

Some time after this, in 2009, Themba saw an advert in one of the local newspapers where they were looking for people to work at Spar in Nhlanguano. He applied for the job and was hired. He has been working for Spar for over a year now and says his life is no longer the same.

"I am now a born again Christian, something that





Themba Nkambule's story...continued

has encouraged me to come out and speak about my status, as well as encourage other young people not to make the same horrible mistakes I made," he says.

He concludes by encouraging other people, especially Christians who are on ART, not to stop their treatment without being told by a doctor to do so.

"As a Christian I believe that God heals, however, I would not encourage people to give up their treatment without a doctor telling them that, indeed, they have been healed," he says, in conclusion.





Vukani Simelane's story



Highlights:

- † Family is wiped out by HIV & TB because of failure to seek hospital help and strong belief in witchcraft within the whole community
- † Children infected with drug resistant TB by their parents, who fail to seek the relevant medical help
- † Defaulting on TB treatment leads to drug resistance and death
- † Difficulty of MDR TB treatment injection phase is exacerbated by socio-economic challenges faced patients, especially those on DR TB treatment

As we approach the Simelane homestead, there is an eerie quietness about the place, which leaves one feeling uneasy. Although there are various houses, mostly mud huts, all, except one, remain closed and bereft.

Sitting down to chat to this family, a story of a family totally wiped out by HIV and its co-infective cousin, TB, unfolds. The only remaining member of this household is an old lady, who can only walk with the aid of a stick and has basically become an invalid, due to old age. The heartache of seeing her children die one after the other has also contributed to her ill health.

Her nearest neighbour is her only remaining child, daughter Ntombikayise Simelane. Sadly, Ntombikayise also came close to death due to HIV

and MDR TB co-infection.

Back at the old lady's homestead, the only brick house in the yard is partly occupied by two young boys, 14 year-old Vukani and his 11 year-old brother. The children's father, a son to the old lady, passed away last year from MDR TB.

Their mother passed on in 2006 from symptoms suspected to be related to HIV. She never got diagnosed with HIV or TB because the family never sought hospital help. According to Ntombikayise, it is a common belief in their community that, if someone is sick, they have probably been bewitched. As a result, the people waste a lot of time seeking help from traditional healers for something that requires a different kind of treatment.

Ntombikayise is convinced that both her brothers and their wives died from HIV related illnesses. This, she says, is because some of their children passed away just after birth. One of her late brother's daughters, a nine year-old girl that she lives with, is HIV positive and on antiretroviral treatment (ART)

Vukani and his brother also spend most of their time at their aunt, Ntombikayise's place, as she is the one looking after them due to their grandmother's invalidity.

As if the family does not have enough problems, Vukani, a Form 1 student at Hosea High School, is also on MDR TB treatment. The young boy's illness was only discovered around the same time of his father's death. He had been visiting his father, who worked in Big Bend, when he fell ill. He was coughing endlessly, had night sweats and fever just like his father. Father and child were admitted at the company clinic for treatment.

Vukani's father, who had been diagnosed with TB in the past, had defaulted on his treatment on various occasions. By the time of his admission he was suspected to have drug resistant (DR) TB. Unfortunately, because of his failure to adhere to treatment and leaving the situation until too late,



Vukani Simelane's story...continued

he eventually died while undergoing treatment at the clinic. He also infected his son, who was now left all alone at a clinic in another region of the country.

Back at his paternal home, Hosea, in Shiselweni, his family had to prepare yet another funeral.

Ntombikayise, who is also on MDR TB treatment, then approached the MSF nurses treating her to assist in arranging for Vukani's transfer back home, to continue his treatment in Nhlanguano. He was started on MDR TB treatment in April 2009 and had to endure daily injections for 6 months before he was taken off the intensive phase to continue with the pills.

"If all goes well, Vukani will complete his treatment in April next year (2011) because MDR TB takes about two years to completely cure," explains an obviously well informed Ntombikayise.

During the six-month injection period, Vukani had to pay a E16 daily return fee to get his injection at Silele Clinic, an arrangement made by the Nhlanguano Health Centre TB Clinic for him to access treatment a bit closer to home.

This meant that Vukani only arrived at school around 10am every day, yet he was doing his last year of primary school. Grade Sevens in Swaziland write an external examination at the end of the year, so it is usually an intensive year for both their teachers and the students. Grade Seven classes started at 6am each day and Vukani could only arrive four hours later. His school work was bound to get affected.

"I was failing almost all the tests because I wasn't there when they were teaching most of the topics we were tested on," he explains.

Vukani thanks God that he managed to get a Second Class pass in the Primary Certificate Examination despite all these challenges.

He is now in Form One and is happy that he no longer has to miss lessons everyday. He now only goes for a check up and drug refills once a month.

He says teachers and fellow students at his school

have not discriminated against him because he has a deadly form of TB. He believes the fact that his aunt, Ntombikayise, went to the school to explain about his sickness helped. MSF TB nurse, Rudolf Makwara, also went to make a presentation to the school to ensure that teachers and students did not fear Vukani's disease and understood what preventative measures to take in their classes. This resulted in Vukani being well accepted, just like any other student.

Although he admits that getting injections everyday was difficult, Vukani says he persevered because he knew that he would get better.

Vukani's dream for the future is to become a doctor.

He says, "I wish to become a doctor when I finish school, so I can treat and help others the same way I have been helped by the doctors treating me."

Ntombikayise, who used to survive by selling fruits and vegetables at a local market, is moved close to tears by her nephew's words.

"I am so amazed that my brother's son wishes to be a doctor because we have had funerals in twos and threes in our community and our family, simply because people failed to seek the right treatment," she laments.

She says her brothers, their wives and some of their children would still be alive today, had they known better. Treatment is available for both TB and HIV.





Vukani Simelane's story...continued

Her words are reiterated by her mother, Vukani's grandmother, who speaks in a low resigned voice, "Every homestead is perishing; only children and old people like us are left behind, yet we no longer have the strength or ability to do anything, so we often sleep on empty stomachs."

The family now survives on handouts from other people, including MSF nurse, Rudolf Makwara, who visits patients in their homes and sees how bad the situation is. Ntombikayise also takes odd jobs here and there, like doing someone's laundry; even though her own health is still not very good.

All the challenges she has faced and still faces, including losing three of her children, aged 6 years, 4 years and 15 months, while she was admitted in hospital in Mbabane in 2004, being abandoned by her man with the pregnancy of her last child, have not phased Ntombikayise's spirit. If anything, the

hardships and seeing her family perish in this way, have made her very determined to open the eyes of her community about HIV and TB.

"A lot of people in our community start TB treatment, but because there is no money to go to hospital, they end up giving up, resulting in the development and spread of drug resistant TB," she elaborates.

Ntombikayise says this, coupled with the community's strong belief in witchcraft, is what is killing her people.

"Where we can, we encourage family members and neighbours to test for HIV and screen for TB, but they don't listen.

"Even this morning, some hired cars to go to traditional healers yet the symptoms are clear that they probably have TB; the sweating, coughing non-stop, weight loss, etc," Ntombikayise laments. Still, she believes with more health education and intensified countrywide awareness, especially on TB, health seeking behaviour can be improved. This, in turn, would curb the spread of TB, especially the drug resistant forms of the pandemic, as well as HIV.





TB Nurses Praised

Praise for TB nurses at Nhlango Health Centre

Thank you for coming up with the idea of establishing a patients' stories magazine. I pray and believe that your efforts will go a long way in helping and informing our people.

You know, very few people have their obituaries written and read whilst they are still alive. But I would love to say a few things about the nurses at the Nhlango Health Centre – TB Clinic, where I am currently taking my medication. They are truly God given and are one of the rare humane nurses in the country, especially in this given time. Do not get me wrong, all nurses are good, but some are better than others.

These ladies treat us (patients) like family. Committed is their first name; then they have all



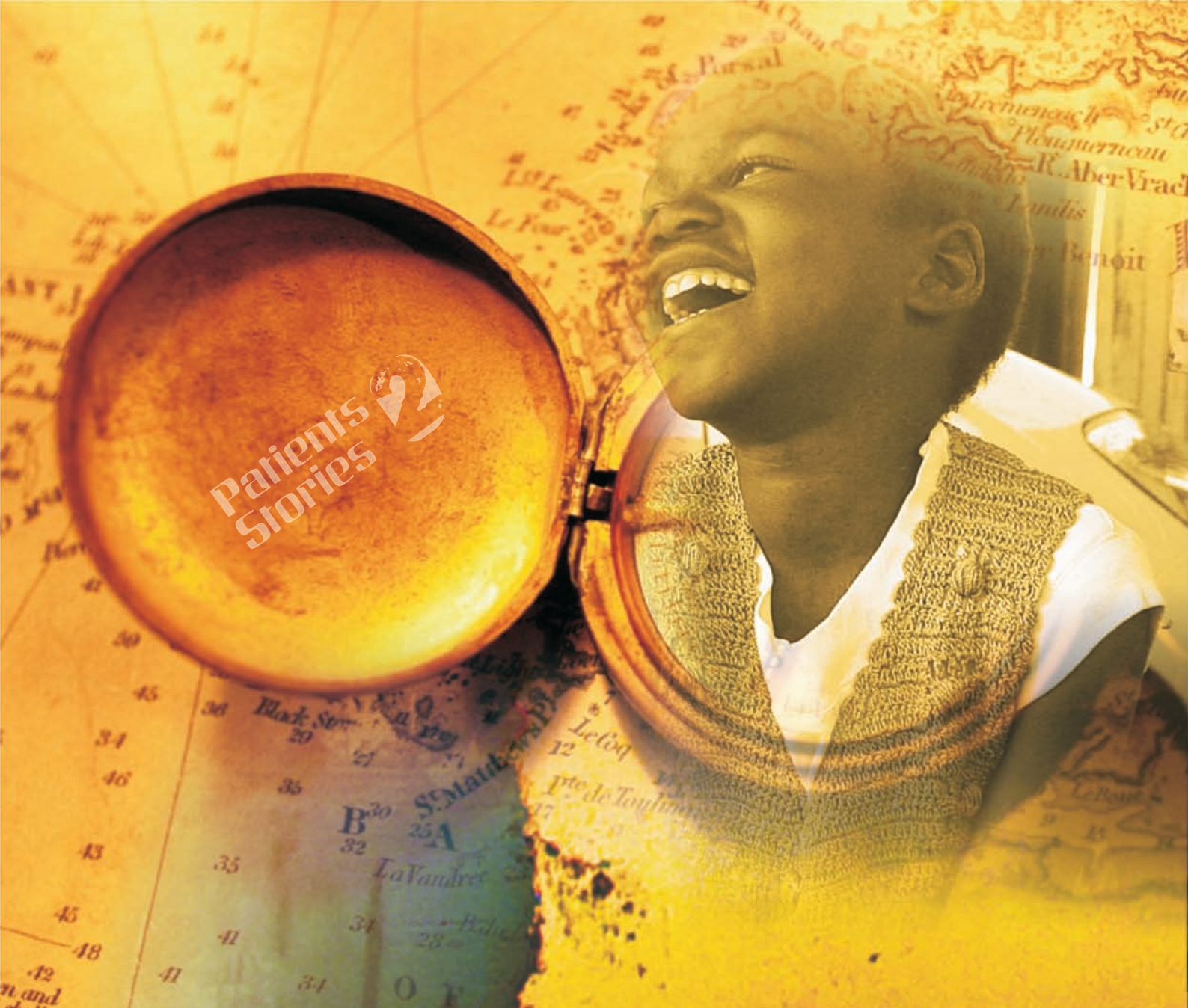
the other names anybody would like to give. Names like, Punctuality, Organisation, Order, Discipline, Love, Perseverance, Patience (Eish! Phela TB patients can be very naughty and nasty at times), the list is endless.

I know two of them by their real names; Sister Joyce and Dudu. As if to live up to their names, these girls truly bring joy and comfort to their patients.

So, if you live around Nhlango and you suspect that you have TB, do visit these ladies.

Keep up the good work ladies and may the Almighty God bless you as you continue to seek His guidance in serving His people.

Anonymous MDR TB patient: Nhlango



Patients
Stories

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Swazi people
fighting HIV & TB together in Shiselweni

Médecins Sans Frontières - Swaziland
Plot 392, Lukhalo Street
Dalriach East, Mbabane, Swaziland
e-mail: msfch-swaziland-iec@geneva.msf.org