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"I never gave up hope"

By the time Mciniseli Malaza was admitted to Moneni TB [tuberculosis] Hospital in Manzini, Swaziland for pneumonia, the six-foot tall man weighed just 41 kilograms. He was HIV-positive but, despite a CD4 count of about 200, was not on antiretrovirals. He was also coinfected with tuberculosis.

"I had a fever and difficulty breathing," Malaza says about his initial three months in hospital, from March to May 2010. When he didn't respond to the drugs for regular TB, he was diagnosed with something far worse: extensively drug-resistant TB (XDR-TB).

According to the World Health Organization (WHO), XDR-TB is resistant to at least four of the core TB drugs, including the two heavy-hitters: isoniazid and rifamipicin, plus all the fluoroquinolones and at least one the three injectable second-line drugs (www.who.int/tb/challenges/xdr/faqs/en/index.html).

Malaza stayed in hospital another year, undergoing daily injections and taking up to 24 tablets daily. His wife quit her job at a textile factory to care for him all day. His sons, then 7 and 1, weren't allowed in the hospital. Some patients would walk to the gates to see their children, but Malaza couldn't manage the small hill. It was a dire time. A patient he befriended died, not surprising, given the 30% to 40% mortality rate among patients at the Moneni TB ward. "That made me very sad," he says via an interpreter.

"There was one point in the hospital when I wondered what I'd done to deserve this," says Malaza. "But at no point did I lose hope. I continued to fight for my life."

Nearly three years later, Malaza sits in a new outpatient facility run by Mèdecins sans Frontiéres (MSF) in Matsapha, just outside the city of Manzini and near his home in Mhlaleni. He's on antiretrovirals and in the final year of treatment for XDR-TB but says he feels healthy and strong.

"I feel very lucky to have received the treatment and survived," adds the 30-year-old. "I've seen many people die in my family from TB, including two close relatives."

That makes Malaza one of the lucky ones — lucky in the first place to even get treatment. There were an estimated 12 985 new cases of TB in Swaziland in 2012, but only about 4000 people on treatment. And of the estimated 1100 with drug-resistant TB (DR-TB), only about 600 are being treated, according to MSF.

Malaza's equally fortunate to have survived without any of the adverse effects typical of drug-resistant TB treatment, such as hearing loss and depression.

Hearing loss, which afflicts about 10% of patients with TB who've been treated, and which may be permanent, is linked to use of injectables: kanamycin, amikacin and capreomycin.

Depression, and sometimes psychosis, are linked to the use of terizidone or cycloserine, but may also be related to HIV.

Treating patients with TB is very difficult to manage and many stop taking their treatment, says Dr. Kazi Arif Uddin, the physician in charge of DR-TB at the Matsapha

Comprehensive Health Care Clinic. Generally the symptoms disappear once the patient stops taking the medication.

The longer a patient is on the TB treatment cocktail, the greater the risk of adverse effects. Regular TB takes six months to treat, DR-TB takes two years. Patients like Malaza with XDR-TB, are on drugs for three years, and so the risk is particularly high. Yet his only adverse effects were some vomiting and nausea, a rash and bleeding at the injection site. He's been lucky in other ways too. His wife and sons, now nine and three, continue to test negative. Extraordinarily, his employers continued to pay him throughout his illness. He'd worked for a food and dry goods distributor for seven years and has been back at work since August.

"Most people get half their salary for three months. Then they get laid off," says Gomolemo Shabangu, the psychosocial supervisor for DR-TB patients at MSF's Matsapha clinic. Malaza has been receiving his treatment at the clinic since his discharge in August and says he likes it because he saves the bus fare to Moneni TB hospital, while receiving psychosocial counselling.

He seems unsure about how long he has to stay on medication.

"Proper communication hasn't been done," admits Shabangu. Malaza will be finished treatment in April 2013, she explains.

"I will celebrate and thank God," he responds, adding that he wants to help others by becoming an expert client; one of a cadre of health workers who are in treatment for HIV, and sometimes TB, whose task is to encourage others to get tested and to get treatment if necessary.

"I'd like to motivate others and encourage them to stay on treatment," says Malaza. "TB is treatable if they stay on, but it's difficult, especially PAS [the antibiotic para-aminosalicylic acid], and the nausea and vomiting you get from it, but it's one of the most important drugs."

Shabangu says PAS packets litter the ground under patient's windows. "They hate it and toss them."

Malaza understands that. "I'd like to encourage people to be very patient with nurses, especially during injections. People fight with the nurse and find excuses not to take [the medication]."

Malaza is filled with other plans for his future as well, including opening a retail store. Three years ago, any future at all seemed quite unlikely. — Barbara Sibbald, *CMAJ*

Editor's notes: Fifth of a multipart series. Barbara Sibbald's accommodation and transportation while in Swaziland were provided by Médecins sans Frontières.

Part 1: **Making sense of the world's highest HIV rate** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4315).
Part 2: **The face of an epidemic** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4320).
Part 3: **Responding to Swaziland's dual epidemic** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4334).
Part 4: **New diagnostics, available care offer hope to patients with drug-resistant tuberculosis** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4334).

For other patient stories, the TB & Me website features a collection of blogs written by people living with MDR-TB in different parts of the world (http://blogs.msf.org/tb/).

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