

STRENGTHENING UGANDA'S SYSTEMS FOR TREATING AIDS NATIONALLY

Better Healthcare: With the Right Diagnosis, I Got the Right Treatment

Bernard narrates his experience being diagnosed and treated for multi-drug resistant tuberculosis



Bernard—a 42-year-old construction worker—is one of the 24 patients who successfully completed MDR-TB treatment at Mbale RRH. He is now a trained MDR-TB expert client by the MOH and a change agent in his community. He tells his story contending with MDR-TB:

According to the Global Tuberculosis Report 2014, increased use of new diagnostics is ensuring that significantly more TB patients are correctly detected.

The USAID Strengthening Uganda's Systems for Treating AIDS Nationally (SUSTAIN) project is working closely with Uganda's National Leprosy and TB Program to strengthen the capacity of public hospitals to effectively manage and prevent both susceptible and multi-drug resistant TB (MDR-TB). By December 2016, up to 245 patients diagnosed with DR-TB were initiated on treatment at the seven treatment centres supported by USAID/SUSTAIN.

At Mbale Regional Referral Hospital, screening and initiating DR-TB patients on treatment started in 2013. To date, 24 patients have successfully completed their treatment at the hospital, and an additional 36 patients are still undergoing MDR-TB therapy.

My MDR-TB diagnosis

In 2014, while on duty in South Sudan, I felt feverish, [so I] went to a medical doctor who recommended antibiotics for five days. I wasn't getting better. On the third encounter with the doctor, I was tested for malaria and typhoid

whose results turned out negative. The doctor suggested that an x-ray test be performed. At this point, I decided to return to Uganda and continue the investigations at home.

I took an x-ray test and once I had the results, decided to call a nurse friend who lives in Kampala to help me get a diagnosis. I travelled to Kampala and met a team of doctors who, upon looking at the x-ray results, asked if I had been coughing, feeling feverish or sweating in the night—signs which I was experiencing at the time. I was given capsules that I had to swallow for three days so I returned home. After three days, there was no change. Because I had already travelled back to Mbale, this time I decided to go the Mbale Regional Referral Hospital (RRH) for more investigations. Here, at least I was sure that I could get transport to bring me back for reviews.

At Mbale RRH, I presented my x-ray copy to the doctor in the outpatient department and narrated my story. The doctor asked me to take another x-ray test but also provide a sputum sample to check for TB bacteria. As I returned with the new x-ray results, he referred me to the TB ward where he said I would receive the sputum results. To my

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surprise, the TB In-charge requested that I provide a fresh sample of the sputum—and this time early morning sputum—so I went back home with a container. I delivered the sputum sample in the bottle the next day, and I was told the results would be ready in a week's time. I was feeling frustrated but had no choice. I did not wait to be called but instead rang the nurse at the TB ward who confirmed that the results were ready. The In-charge explained that I had TB but this type was drug resistant. In addition, the nurse told me that they had ordered for my drugs so they would call me when the drugs are available. It took only four days for my drugs to reach the clinic. I was immediately called and told to come with two treatment supporters to discuss my treatment plan.

Treating my MDR-TB side effects

“Bernard, the treatment you are going to start is for two years and you will be coming to the hospital daily. This treatment consists of daily injections for the first six months but you have to ensure that you eat well and drink more fluids while on treatment,” said the TB In-charge. When I heard of injections for six months, I wondered how on earth I was going to receive over 180 injections without a break. I immediately remembered how my grandfather used to boil the syringe with a long needle like a spoke of a bicycle to inject us whenever we were sick. Sometimes, we would bleed after the injection.

Together with my elder sister and cousin brother—who were my treatment supporters—we listened to their expectations from us, side effects of the drugs and how to prevent my family and friends from [getting] the infection. I was then asked if I was ready to start the medication; I didn't agree. For my treatment supporters, they couldn't take such news and quickly confirmed that they would be there for me. My worry

was that I had not been eating well so I could not start on such strong drugs. I preferred to start MDR-TB treatment after three days when I would be sure that I had eaten. We then signed forms of consent before I could start my treatment.

Within a week of starting MDR-TB treatment, I was already experiencing side effects like the ringing ears, dizziness, joint pains and headache. To my surprise, old as I am, I grew breasts, like a teenager and never wanted anyone to touch them because they were painful.

In September 2016, Bernard successfully completed his treatment of MDR-TB. Now Bernard helps others get the treatment they need to cure MDR-TB.

The nurses kept encouraging us [patients] to always tell them the side effects such that they can help. Because we were the first patients on MDR-TB treatment in the region, we thought the nurses and doctors were conducting research on us. There were no people to give us testimonies having cured from the infection. What kept us going is that the side effects were reducing month by month. More so, I didn't get discouraged because I knew that if I died at the time, my children would stop their education and that there was no one to take care of my six children. The last born [baby] having been born while I was on treatment.

Once I was five months into treatment, I was transferred to receive treatment at a health centre near my home to reduce transport costs. However, at the new site, I was the only client with MDR-TB and used to wait under a tree until the health worker saw me. I felt so discriminated, but again knew that it

was to protect others from the infection. I received my treatment here until I completed. However, the health team from Mbale regularly came to check my progress visiting both the healthcare facility and my home to encourage and check family members if they contracted the infection.

To protect my family from getting the infection, I slept in a separate room. My wife had to stay away from home at her mother's place for two months after giving birth to our last-born baby. It hurt me that I couldn't go to the hospital where my wife delivered, neither could I see nor hold the baby immediately.

Financing my treatment process

My savings from the construction work helped to facilitate my transport, accommodation and medical tests including x-ray test while I was still conducting investigations. Even my treatment supporters, I was the one giving them transport for the first month until the money was finished.

Fortunately, the health workers explained that there was a USAID-funded project called SUSTAIN which was contributing 120,000shs for each patient to cater for transport and food during the treatment. This fund was such a relief because I don't know how life would have turned out.

I could not believe that I was not given any drug the day after I completed treatment. But the health workers still followed me up regularly (after four days, two weeks, a month) to confirm I was cured. In November 2016, I was selected and trained by Ministry of Health as an MDR-TB expert client. I now participate in health education for current patients to share my story. I also sensitize people in my community on the signs and symptoms of TB and MDR-TB. For those who don't know where to start, I escort them to the TB ward to conduct tests.



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