

The Burden of Living with MDR-TB: Caleb's battle with multidrug resistance TB

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Figure 1: A section of Community Health Volunteers and KANCO Eastern region coordinator at work in Kitui County

Multi Drug Resistant Tuberculosis—MDR-TB may sound strange to many people yet it is on the rise globally with about 480,000 cases and is affecting approximately 917 people annually in Kenya. Kenya has been ranked among high TB burden countries globally. MDR-TB is also very expensive to treat since it costs over Kshs 2 million for a period of up to 24 months compared to Kshs 8000 which is the cost of TB medication for a period of six months. According to TBfacts.org only 52% of MDRTB patients who started treatment in 2013 were successful as at 2015. Caleb Munywoki, a 30 year old resident of Mwingi constituency, has been battling MDR-TB since November 2016.

MDR-TB is a Tuberculosis infection caused by bacteria that are resistant to treatment using two

of the most powerful first-line anti-TB medications: isoniazid and rifampin. This strain of TB could arise from improper use of antibiotics, including use of improper treatment regimens or improper dosage which could include failure to complete treatment, or transmission of this strain of TB through inhalation of the bacteria according to World Health Organisation (WHO). According to the TB Prevalence Survey 2017, there are identified high TB burden areas such as refugee camps. This is attributed to an influx of people from Somalia and poor surveillance/screening systems at the volatile borders.

Although Kenya has adopted the new MDR – TB treatment regimen, which takes about 10 to 12 months, Caleb is on a long term treatment regime which takes approximately 20-24 months since he had already been started on it. According to Medscape patients receiving therapy for MDR-TB are at high risk of treatment failure owing to the second line agents which can be expensive, have significant side effects, and require longer duration of treatment as they are less effective than first line regimens. The WHO guidelines on drug susceptibility recommends that therapy

should be patient specific, with appropriate monitoring and patient education to achieve optimal response to therapy and minimize medication related adverse effects.

With the Gene Xpert technology, a molecular test for TB which detects the DNA for TB bacteria through a sputum test, diagnosis for MDR-TB has improved tremendously compared to an earlier culture/microscopy test where the test results would be shipped from South Africa some years back. With the new technology Caleb got his test results in one day at Mwingi District Hospital which is one of the sites supported by the Global Fund to fight TB, Malaria and HIV pilot GeneEXpert.

The Mwingi Chest Clinic is currently managing two cases of MDR - TB and 197 cases of pulmonary TB. Kennedy Saidi, a nurse at the clinic says that the facility has been very keen on HIV testing among TB clients to identify cases of TB/HIV co infection for effective treatment. “At least 98% of all clients who have been tested and 32 clients have tested positive for HIV” he say and adds that this is a key milestone in implementing the TB/HIV collaborative interventions. Caleb expresses his delight on the opportunity to test for HIV saying that the results addressed his fears that MDR-TB is related to HIV. “I was tested for HIV and my results were negative.” he said.

Like most MDR – TB patients who cannot engage in productive activities such as employment or income generating activities, Caleb had to drop out of school where he was pursuing a Certificate in Electrical and Electronic Engineering. His ailing health forced him to close his electronic shop in Mwingi town in order to seek treatment. He became dependent on his parents who live in the village for his basic needs. After 8 months in the treatment, Caleb was given Kshs 6000 from the facility which is provided by AMREF as patients’ upkeep support. The cash support program is supported by the Global Fund to fight AIDS, TB and Malaria (GTATM). Caleb has been saving part of the money with the hope that one day he will get back to college and finalize his certificate course.

Despite the fact that Caleb has been on direct observed treatment for the last 11 months, the journey has been very tough for him. For the first eight months, he had an injection every day. According to Kennedy the nurse attached to the chest clinic, intravenous treatment is a huge burden to many patients. This is because the treatment takes 20 months hence a patient has to visit the hospital every day for the 20 months. Caleb explains that being on MDR-TB treatment, there are enormous challenges. “I had serious drug-reactions which caused itching all over my body,” he says and adds that he however was assisted by his parents to buy some medication to ease the itching. He further notes that inadequate nutritious food also causes adverse effects to a patient on MDR-TB treatment. At one point Kennedy had to bring him food and money for sustenance.

Caleb’s experience highlights key challenges that people living with MDR - TB face each day. One of the challenges is the need for accessible and strong health systems for diagnosis and treatment. Due to the availability of the GeneXpert in Mwingi District Hospital, many patients are now able

to have timely results hence access to early treatment. This underscores the need to ensure that health facilities have all the required systems in place including human resources, if they are to effectively provide MDR – TB services.

Championing a Community led TB Response

KANCO is currently working with 30 Community Health Volunteers CHVs in Eastern region and 700 countrywide for a community based TB response with support of the global Fund to Fight AIDS, TB and Malaria through AMREF Health Africa. The CHVs have been instrument in supporting Caleb.

The Community Health Volunteers (CHVs) remain a key component of TB response. CHVs from Mwingi have remained close to Caleb. In addition, they have been able to support TB patients to access the Mwingi District Hospital Chest Clinic during the nurse's strike as the other neighboring government health facilities were closed due to lack of personnel.

To engage informal service providers in TB response, KANCO is working with Community Health Solution (CHS) under the TB-ARC project funded by USAID in Eight counties.

At national KANCO has been spearheading TB advocacy toward increased profile and community engagement in TB response. KANCO has been part of global movement advocating for increased TB funding and political commitment.

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