

PEOPLE WHO START TAKING HIV DRUGS SHOULD STRICTLY ADHERE TO PROCEDURE

# Skipping ARVs causing blindness

BY ELVIS BASUDDE

Stephen Odongo, 45, from Ekamu village in Amuru district, suddenly lost his sight. He was living with HIV and on treatment. I found Odongo at Otwede Health Centre III in Amuru Town Council, where he had been accompanied by a relative to access antiretroviral therapy (ART) services. He had travelled 70km to come to this health facility.

Doctors explained that his blindness was because he did not adhere to the ARVs that he was taking. According to Ismail Oyet, a health worker at Otwede, non-adherence triggers off a dormant virus called cytomegalovirus (CMV), which causes blindness.

## ODONGO'S STORY

According to Oyet, Odongo is an S4 dropout, who has been living with HIV for 12 years now, after being diagnosed in November 2005, when he was 33 years old. Since he was not adhering to the treatment, he got a CMV attack, which blinded him in 2012. His CD4 count was 12 (normal is 500-1,500) and his viral load was in millions.

Odongo confesses that he has not been taking his ARVs regularly and he attributes this to the long distance to the health centre and lack of nearby health facilities.

The distance from Ekamu, where he lives, to Otwede, where he accesses his ART, is 70km, without taxis or bodabodas. On the appointment day, he has to be escorted and they must start the journey four days before.

When he uses a bodaboda, he requires over sh80,000 per visit. But on many occasions, he has failed to raise money for transport.

Odongo gets medicine for a month, meaning he has to return for refill every month. There are times when he cannot go to hospital and spends four months without swallowing his drugs. It is little wonder that Odongo failed to adhere to treatment.

## WHAT IS CMV?

Christine Lisa Irumba, a clinical officer and a palliative care specialist at Hospice Africa Uganda (HAU), explains that CMV is in the same family with viruses that cause chickenpox. It spreads easily from one person to another and can cause a blister-like rash, itching, tiredness and fever.

Dr Lawrence Drew from the University of California, San Francisco, says CMV is a common virus that infects people of all ages. Once CMV is in a person's body, it stays there for life and does no harm or show signs or symptoms. However, for people with weakened immune systems, it can cause serious health problems.



Odongo (left) being helped by his aide to receive medication at Otwede Health Centre III in Amuru Town Council. Right are some of the ARVs given to HIV-positive patients

The most common problem is Cytomegalovirus retinitis, Dew says, which is an inflammation of the retina of the eye that can lead to blindness.

"It occurs predominantly in people whose immune system has been compromised, especially in people living with AIDS," he says.

Dr Paul Muwanga from Njeru Clinic has been treating eye conditions among HIV-positive people since 1999.

He says CMV affects the retina, the neural tissue of the eye. If the tissue is damaged, it cannot be regenerated. However, if the part of the retina that is responsible for vision is not affected, the condition can be treated.

Muwanga says about 75% of

HIV-infected people will experience some form of eye problem, while about 10% will go totally blind in one or both eyes. He says blindness in immune-compromised people like Odongo is usually a result of a weakened immune system.

Since treatment is expensive, he says, prevention is much more important through adhering to the ARVs regime.

## ADHERENCE

Taking medication every day is not as simple as it sounds. Molly Nakiwala, who has lived with HIV for over 15 years, says the drugs weaken the body because they are strong and if one's immunity is low, one can easily give up on medication.

Nevertheless, Dr Andrew Kambugu, the head of research at the Infectious Diseases Institute, insists that adherence is imperative to guarantee the effectiveness of antiretroviral therapy, which has led to a substantial reduction in HIV-associated deaths and diseases.

He says the goal of ARVs is to suppress viral replication.

Kambugu says ARVs attack the virus directly and stop it from multiplying in the body. When one takes medicine, their immune system improves. But when one does not adhere, their immune system can go back under 100 cells, which health workers call treatment failure.

According to Kambugu, the key consequence of non-adherence is the virus becoming resistant to the drugs and one has to be started on second line treatment. If one does not adhere to the drug schedule there too, the virus becomes resistant.

When there is virological failure, he says, the virus multiplies and destroys the immune system and the patient gets what is called immunological failure and starts getting opportunistic infections such as cytomegalovirus, that is probably what befell Odongo.

Mild CMV infection is usually not treated as it subsides on its own. Most healthy people will recover without complications and do not require ARVs. However, in those with a weakened immune system, CMV can cause serious diseases.

When the infection threatens life or eyesight, ARVs can clear it.

Dr Andrew Kambugu, the head of research at the Infectious Diseases Institute (IDI), says statistics show that in some regions in Uganda, as many as 80% have been exposed to CMV, but their immune system is able to control it. They do not even get to know because it rarely causes symptoms.

"It is people living with HIV who are more vulnerable to CMV because their CD4 cells are very low and can easily allow the virus. CMV is the most common cause of blindness among AIDS patients, whose immunity has gone down. Once your CD4 count goes below 100 cells, you can get infections such as meningitis and CMV," Kambugu says.

## ADVICE

Dr Josephine Birungi, a research manager at TASO, advises people on ARVs to adhere to treatment to avoid CMV attacks on the retina. This is not common unless the person on ARVs does not adhere to the drug schedule, she affirms.

Stella Kentutsi, the executive director of the National Forum of People Living with HIV Networks in Uganda (NAFOPHANU), says HIV is a manageable disease if effectively treated with ARVs. However, if left untreated or

if medication is not taken as prescribed, HIV can cause illness and death. HIV treatment stops the virus from multiplying in the body.

"Unfortunately, we continue to have sporadic stockouts of ARVs in Uganda, which forces many People living with HIV to miss medication, thus poor adherence. Failure to adhere to the treatment does not only cause visual impairment, but also leads to other complications such as physical disability," she warns.

Kentutsi adds that poor adherence to HIV treatment is also escalated by stigma and discrimination, lack of food and inadequate counselling.

She calls on the Government to ensure constant supply of ARVs, as well as increased funding for HIV treatment.

Kentutsi says there is also need to invest in strong community structures – adherence counsellors and peers to follow up clients who are not responding well to treatment.

