

Charles Luka Mukanga

Kampala, Uganda

It took three years after he was diagnosed for Charles to tell anyone he had HIV. Finally, he felt confident enough to share his status with a friend at his work. Within hours, the colleague had told their supervisor. Charles was abruptly fired from the job. This was 1997, at the height of the AIDS pandemic, before treatment was available in Uganda.

It would be five more years – and only after he had grown desperately ill – before Charles shared with anyone else that he was HIV-positive. Confronted with death, he discovered he no longer cared if people knew his status. Instead, he actually found himself desperate to tell his story in hopes of convincing other Ugandans to protect themselves from his fate. Though he could barely stand upright, he joined a drama group organized by The AIDS Support Organisation in Kampala.

“ We were so open to the extent of going even on TV, radio, talking about our HIV status. Singing. Giving testimonies. People here in Uganda, we just need to touch something to see. You bring a skit, and then you leave questions which are unanswered. That’s what we mean when we say that’s community dialogue. You cannot just go there and say, ‘Hey, this and this.’ No. Give them something which triggers their brain. And then they start discussing. You can discuss with people even two hours.

There were two songs which were my favorites. “United Against AIDS” and “Bridging the Gap.” Those were my two favorite songs. When you performed, like giving a testimony, sometimes you can break. You can get nervous.

For me, I used to break when I reached the part of losing my wife. There are many things that came in my head. Because for me, I was sick so many times. I was sick. She took me to the hospital and then I came back. For her, because she was diagnosed with tuberculosis, she went to the hospital and came back. It came back again, and it came back again and that third time she did not survive. So I was just thinking that maybe I didn’t do enough. So I used to break when I reached that part.

In 2002, the group performed for Bono, the U2 frontman and humanitarian, when he visited TASO¹. After the performance, the singer agreed to pay for each member of the troupe to start treatment. That is how Charles' life was saved.

¹ The AIDS Support Organization (TASO) is an indigenous HIV and AIDS service initiative, registered in Uganda as a non-governmental organisation.

As drugs became more widely available, Charles watched in consternation as the focus on stigma eased. The United States helped build specialized drop-in centers where people living with HIV could discretely access treatment. So long as they took their daily pill, no one would ever know they were infected. The funding for Charles' drama group disappeared 10 years ago.

Now the uncertainty created by the Trump administration's foreign aid cuts has raised questions about the future of those centers. Charles becomes almost mournful as he predicts that with their closing, the stigma that has been allowed to lay dormant will now resurge.

The government has an idea. They are ready to say that HIV clinics are going to be integrated in the outpatient departments. But there is a lot of stigma and discrimination. These people here in Uganda, even a person can be in Kampala and get the drugs from Masaka* because they don't want people to be knowing. But if you tell them now everything is going to be integrated in the OPD...*

He shakes his head.

Things will never be the same when they know that you are HIV-positive. Things will never be the same.

You know, here in Uganda, we thought at least we've done something when it comes to stigma and discrimination. But when you reach the communities, that's when you will understand that people fear a lot to be known that they're HIV-positive.

You find that people can live together, a man and a woman. One is HIV-positive and then doesn't want to disclose to a partner. For them, they think that if someone knows your status, you're going to face it rough. You're going to be stigmatized. You're going to be abused. Even people are being chased

away from their work, if they are known that they are HIV-positive. Even up to now, it is still going on. So you cannot say everything is going to be okay.

People thought that because of the medication, they no longer needed to put emphasis on sensitization. But understanding the facts about AIDS has never been something to joke with.

If stigma is left unaddressed, Charles is convinced people will reject services that carry any risk of revealing their status. But he senses that there is no appetite – and no funding – to revive the old initiatives.

What are you going to use when you are sensitizing? If we are to have dances, we need the drums, we need the uniforms. We need the personnel. I don't think today when we say that we are going to have a drama group which is going to sensitize people and we need people living with HIV, I think you can't get even five people.

When I ask him, toward the end of the conversation, where is currently working, Charles is reluctant to answer.

If you have like a business thing and people understand that you are HIV-positive, they may not come buy things. Because people don't know the way it is transmitted. We are still back in those days, when people fear to be near a person with HIV.