



Breaking the Silence

Tom Fikiri Masarara has experienced a journey of survival and hope.

January 6, 2025 By Tom Fikiri Masarara

I'm a 51-year-old man who is blessed to have a lovely wife and three beautiful children. We are originally from the French-speaking Republic of Burundi, which is situated in East-Central Africa, bordered by the Democratic Republic of the Congo, Tanzania and Rwanda. Currently, we live in the township of Lehae, a suburb of Johannesburg in the Republic of South Africa. For 17 years, we have lived as asylum seekers.

I am a living testimony of survival and that there is hope beyond an HIV-positive diagnosis. Most people in the world no longer consider HIV a death sentence, but we in Africa often still do.

I fled to the Congo from violence and war between the ethnic groups of Hutus and Tutsis in Burundi in April 1993. I was married in August 1994, when I was 21. After living in several other countries, we finally landed in South Africa in 2009. We can identify with so many other people on this planet who must leave their homeland to seek life elsewhere.

In early 2002, I decided to take an HIV test. I wasn't sick, but I wanted to know my status. I was confident I was negative. Before taking the test, I went through counseling and remember I was asked questions like: "Are you single or married?" "What results are you expecting?" "Are you going to reveal your positive result to your wife if so?" etc.

Some were not easy questions to answer. But I felt like I would be fine with God by my side if I received a positive result.

I tested positive. I was shocked! I didn't know what to do and had a lot of questions and no clear answers. Fearing death was around the corner, I thought of the future of my children. It was a heavy weight on my shoulders. I was only 29 years old. My daughter Rebecca, the eldest, was only 8 years old. My future did not seem promising. My prayers and passion for my children to grow up with both parents is what kept me going.

I began reading everything concerning HIV. I remember one of my colleagues asked me, “Are you now a new researcher on HIV and AIDS? Why are all the books you take from the library about HIV and AIDS? Are you infected by the virus? Tell us early so that we can start preparing for your burial.”

After discovering that nondisclosure can be a “silent killer,” I decided to break my silence. The first person I revealed my status to was my friend Pascal. He told me there is still life inside me, but it still seemed like I was smelling death.

I revealed my status to my mother. She couldn’t believe it and just cried, knowing it might be the end of me soon.

I finally had the courage to tell my wife, and we all went together to get tested. She tested positive as well. Our children all tested negative—praise God!

I became an HIV activist after educating myself and being led by God. I attended many seminars, conferences and training programs, some offered by the World Health Organization. I became a beacon of hope for those living with the virus, also to those who have loved ones who are HIV positive. I always encouraged people to get tested and stressed there is life beyond an HIV diagnosis.

Today I work with the organization the Power of Women and Children (POFWC). We have an orphanage that cares for children infected and affected by HIV and AIDS. For four years, I have been a caregiver for these children and have provided home-based care as well.

POFWC provides food for many people on antiretroviral treatment through donations from other organizations and individuals.

I came to South Africa seeking asylum in 2007. My family joined me in 2009. My daughter finished primary school in Burundi, while the two boys finished primary and secondary education in South Africa. But none of them can access the university because we have been denied proper documentation.

In South Africa, the asylum seeker visa permits are difficult to get renewed. So besides the challenges of living with HIV, we are also stateless citizens of no country. We cannot get passports or visas.

I resisted taking HIV treatment for 17 years, until June 2019, when my health started deteriorating. I was afraid to take treatment due to issues of documentation and fear of deportation as a refugee. Today marks five years on treatment, and I am still strong and aging well.

Breaking the silence is a strategy I use to conquer HIV. Understanding and accepting myself, being positive and trusting God are among the others.

I have learned to have hope, live life and always have faith and perseverance. God wasn't finished with me even when I thought I was finished.

We are still facing stigmatization, discrimination and rejection, but we are still called to be strong.

What three adjectives describe you?

Hopeful, strong and resourceful.

What is your greatest achievement?

Staying alive and being with family in a safe place.

What is your greatest regret?

Not disclosing my HIV status to my loved ones sooner. Keeping it to myself almost killed me.

What keeps you up at night?

Reliving the war in Burundi and being afraid for my life. You could say I have posttraumatic stress.

If you could change one thing about living with HIV, what would it be?

Have better health care and meds available. As asylum seekers and refugees, we cannot get jobs or afford private health care and therefore can't get certain medications. I need to rely on donations.

What drives you to do what you do?

Service to others less fortunate than myself.

What is the best advice you've received?

Trust in God, and be grateful for every day!

If you had to evacuate your house immediately, what is the one thing you would grab on the way out?

My antiretroviral medications.

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