Young HIV advocates stand up to fake news and stigma

Too many people feel shame taking ART, especially young men. Ruele takes his ART in public to help normalise the idea of taking medication

Fatima Shahryar

The majority of young people living with HIV, 60 per cent of the global total, are in Eastern and Southern Africa. Unfortunately, only 70 per cent of them have access to lifesaving antiretroviral treatment (ART) in these 12 countries, where AIDS is still the leading cause of adolescent deaths. Young people face many challenges which reduce their likelihood of accessing HIV services or continuing ART treatment consistently.
Ruele, 26, is a Kenyan young advocate working with Y+ Kenya and is trying to address the major challenge of stigma. Too many people feel shame taking ART, especially young men. Ruele takes his ART in public to help normalise the idea of taking this medication and is using social media to reach young people.

Ruele says: “I tested positive in 2020. I wasn’t expecting it and it devastated me. My first tears dropped. I took my first pill two days later. I was homeless, unemployed, I knew my immunity was compromised. I needed to inform my partner and wanted him to be a source of hope for me – but he left – and it hurt.

“I had no role models or anyone to look up to. With friends we don’t discuss much, it’s just fun. I was going through stages of grief. I was angry at everyone and everything – blaming myself for being ignorant. I had access to facilities that provided information about sexual health. And I ignored it all. I started lashing out at my best friend, wishing he would have it too, to be with me. That’s when I realised these thoughts were not ok, I had work to do.”

“My friend shared a link to become a peer educator. I applied and got the job, which helped me rent a studio apartment. It had been two or three years since I had spoken to my parents. My mum got back in touch and saw me taking the PrEP. I started receiving calls from relatives asking if I have AIDS. I told them I have HIV, not AIDS. I figured, if this my life anyway, perhaps I could educate people on it. On twitter I started learning about people’s challenges of getting medicines. I came across Doreen, who was openly taking about HIV and...
invited me to speak at a regional meeting sponsored by Y+ which is a global network of young people living with HIV. We are all speaking up on the issues that affect us, to change legislation, inform planning of quality services, to improve access, change attitudes and reduce stigma.

“I decided to do a podcast: Sex Ed by Ruele-ations. My friends appreciated my being brave, but I just wanted to let out the pain. My therapist warned that once it’s out, it’s out. I ignored this advice. I could feel people staring, talking under their breath. I got scared because my status and identity are not accepted in the society I am living in. A month later, I got a message from someone in Philippines, saying my podcast gave them hope, they had been considering suicide, but it saved them. I was skeptical of how my podcast in Kenya was reaching Philippines, so I checked online and saw it had reached 40 countries. This gave me strength to continue.

“On social media, I started receiving hateful comments, people saying I deserve HIV because I identify as gay. I realized I was not only anticipating stigma but also stigmatizing myself. Gradually I started seeing myself as a champion to inform about HIV and help people through it. I’m now a director of a shelter for homeless and runaway queer youth in Kenya. When I first saw the people coming there, facing GBV, beaten, in miserable conditions – I knew I had to help them.
“People on TikTok are always posting sad depressing content on HIV, which is frightening people from taking the HIV medication that can save their lives. I decided to take my antiretrovirals publicly. I went to a public parking space and recorded a video of me taking my pills in public. It blew up completely. I had more than 40,000 views in less than a day. I went to the church, the police station, even the supermarket, which got on national news. People in the street would whisper and say ‘I am just like you’.

“Advocating for ART adherence is my main goal. Whoever you are, wherever you are, you can take antivirals. If you are afraid of what people will say, you are putting your health on the line, and it will cost.”

Ruele travelled to Zambia to share strategies with 200 young people at the HIV & Adolescents workshop in Lusaka, attended by the First Lady of Zambia. Ruele is part of the UNITED! Movement of young leaders advocating on key sexual reproductive health rights and HIV issues, calling for young people to have leadership roles in decision-making spaces which affect their lives.

Laurie Gulaid, UNICEF’s Regional HIV advisor, said: “2gether 4 SRHR is a Joint UN Programme in partnership with the Government of Sweden. Sexual Reproductive Health Rights (SRHR) are crucial to our achieving the Sustainable Development Goals, so we are working together with our sister UN agencies to deliver as one on this agenda which is critical for young people.”

2gether 4 SRHR, in partnership with Sida, aims to ensure universal access to sexual and reproductive health rights across Eastern and Southern Africa.