

DAILY LIVING WITH HIV

Visual Stories by Ugandan Youths

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SETTING THE SCENE

ABOUT UGANDA

Uganda is one of the East African countries, bordered by Kenya in the east, South Sudan in the north, Tanzania in the south, Democratic Republic of Congo (DRC) in the west, and Rwanda in the southwest. The country follows a decentralisation system of governance with districts as the largest local government units. Currently, there are 135 districts. Kampala district – in the central region, close to Lake Victoria – houses the capital city, Kampala, while Kabarole district in the western region is home to Fort Portal city, where this project was conducted.

Kabarole district is about 300 kilometres by road from Kampala. The district is structured into urban, peri-urban, and rural settings. The urban and peri-urban area largely consists of Fort Portal city, and its inhabitants are mainly involved in trade and hospitality services. The rural dwellers are mostly involved in both commercial and subsistence farming. As of 2021, Uganda Bureau of Statistics estimated the population of Kabarole district at 354,810 inhabitants, with a population growth rate of 2.3 per annum. The youths make up 21% of this population. The predominant ethnic group in the district is Batooro. They speak mainly Rutooro and other dialects of western Uganda, which belong to the Bantu languages. English is also commonly used, particularly in Fort Portal city. It is an official language and the medium of instruction at the secondary level of education in the country.

ABOUT HIV AND AIDS

The Human Immunodeficiency Virus (HIV) is a retrovirus that enters and replicates in specific white blood cells of the human body, known as CD4 cells. The virus uses the host cell mechanisms to replicate itself into several copies, thereby damaging and destroying the host CD4 cells. The viral load in the body of a person living with HIV thus increases at the expense of CD4 cells. Since CD4 cells are significant for the body's immune response, the individual's immune system becomes compromised and the individual is said to be immunodeficient. The breach of integrity of the immune system paves way for myriad infections that the body would ordinarily ward off. These opportunistic infections are responsible for a variety of signs and symptoms that manifest, and the individual is said to have Acquired Immunodeficiency Syndrome (AIDS).

Antiretroviral therapy (ART) inhibits viral replication, leading to a decline in the viral load and an upsurge in the CD4 count, consequently restoring the defensive competence of the immune system. The individual with HIV thus ceases to experience periodic infections and the physical well-being improves. This situation is maintained for as long as the individual adheres to the treatment regimen and for as long as other immunosuppressants (other infections, malnutrition, stress, some drugs) are avoided or controlled. Antiretroviral medicines (ARVs) therefore prevent or delay the onset of AIDS in people living with HIV.

Living with HIV surpasses the need for medical treatment to include other non-medical aspects of the disease, mostly emanating within social spheres of interface. Many of the challenges and adversities faced by people living with HIV seem to result from deep-rooted and widespread stigma in society. Stigma is social disapproval and discredit, associated with a person's distinguishing characteristic, condition

or circumstances. It evokes negative attitudes, stereotypical beliefs, and differential treatment such as discrimination. HIV-related stigma is rooted in fear, misconceptions, and moral judgment. Lack of knowledge and awareness about HIV transmission, prevention, and treatment breeds unnecessary fear of contagion, even from benign social interactions. Further, socio-cultural worldviews and belief systems (for instance, linking HIV to witchcraft or curses) evoke and maintain negative attributes and devaluing social behaviours towards people with HIV. Moreover, historical associations of HIV with immorality, promiscuous behaviour, long suffering, and eventual death contribute largely to much of the stigma around HIV.

Stigma occurs in overt and covert ways and is both externalised and internalised, with several deleterious effects. This stigma is often internalised by those living with HIV, leading to feelings of shame, self-blame, fear of disclosure, isolation, and despair. The collectively held negative attitudes and beliefs about HIV and people living with it further cause enactment of stigma, as discrimination and differential treatment, by those in their social networks and in their structural context. To avoid stigma, people often opt to conceal their serostatus. The status concealment, however, comes at a high psychological cost due to the vigilance needed to uphold it, and unintentional revelations occasioned by regular medication, frequent healthcare centre visits, and periodic illnesses. Because of this, the stigma may undermine treatment adherence and jeopardise health. In addition, those who conceal their serostatus miss out on the potential support within their social networks and from services. Many people with HIV also struggle with participation in their social environments like communities and in institutions like schools. Since HIV-related stigma is a determinant of much of the day-to-day life, it traverses all the themes in which youths' photos and stories are presented in this book.

ABOUT HIV AND AIDS IN UGANDA

HIV and its associated disease, AIDS, are profoundly impacting the lives of many people globally, who tend to be predominantly situated on the African continent. Most parts of Africa, particularly Sub-Saharan Africa, experience a generalised epidemic with HIV cases reported across geographical boundaries and in all population groups, albeit rather diversely.

In Uganda, Kabarole district is a tourist destination and a transit district to the DRC. This leads to convergence of large numbers of people, a known fertile ground for rapid spread of HIV infections. Kabarole is an already known HIV hotspot with a prevalence in the general population that is higher than the national prevalence of Uganda.

One age-group that has been largely affected by HIV is that of the youths. HIV diagnoses in youths stem from both perinatal and sexual transmissions. HIV in youths can have been acquired perinatally during pregnancy, birth, and breastfeeding of an HIV-positive mother. It can also be behaviourally acquired due to heightened romantic relationship development and sexual activity during adolescence, sexual exploitation, and transactional sex. Irrespective of the acquisition mode, it is mostly during their youth that they become aware or informed of their serostatus. Uganda's policy guidelines, corroborated by international guidelines on disclosure of HIV/AIDS-status, recommend full disclosure for those perinatally infected around the age of 10-12 years. This implies that many people have to contend with the HIV diagnosis during their adolescence, which already tends to be a challenging life-stage.

In Uganda, multi-sectoral and multilevel strategies have been implemented to avert the HIV/AIDS situation. This has led to a general decline in the prevalence of HIV from 18.5% in 1995 to 5.4% as of 2021. HIV counselling and testing services are mainstreamed in Uganda's healthcare system and an HIV test can be performed in all healthcare centres on the request

of an individual or a healthcare worker. The individual has to consent to the test and for the case of children below the age of twelve, parental/caretaker consent is required. Before and after a test, HIV-related counselling is provided and a status disclosure is subsequently made in accordance with the policy guidelines. Following a positive HIV diagnosis, youths are linked to a care and support centre which is ideally in close proximity to their residence and one which can offer the range of care services that is deemed needed by the healthcare worker. At the care and support centre, youths living with HIV are initiated on antiretroviral therapy and they have to remain on ART for the rest of their lives.

Since ART is accessible in Uganda, youths with HIV have been facilitated to live longer, with a life expectancy mirroring that of their peers. Despite the improved prognosis with treatment, youths living with HIV experience a multitude of challenges related to not only their physical health and treatment but also to how society reacts to HIV and those living with it. This in turn can affect their access and adherence to ART. Studies have shown that youths living with HIV often drop out of care and do not adhere well to ART, compared to other age-groups. This is because of HIV-related stigma, fear to be known as living with HIV, resentment of medication, and challenges related to integrating their care and support needs in schooling, among other reasons. As previously mentioned, new HIV cases are on the rise among youths. Therefore, they are an important group to focus on in the fight against HIV/AIDS if Uganda is to achieve the UNAIDS target of ending AIDS by the year 2030.

HEALTH

Hearing about the HIV diagnosis is typically a tough nut to crack. The youths in this project describe it as frightening and discouraging, and as a significant turning point in their lives. Many of them anticipate rapid symptom development and deteriorating health – even a fatal outcome –, which also impacts their mental health and overall well-being. Living with HIV is associated with periodic opportunistic infections, but these can be prevented and diminished through adequate treatment. This treatment includes regular visits to antiretroviral therapy (ART) clinics and taking antiretrovirals (ARVs) every day.

The youths in this project have reached a point whereby they view and portray ARVs as crucial for their survival and health. Seeking and subsequently adhering to treatment, however, is not without challenges. Multiple psychological, social, and physical barriers compromise ART and prevent youths from experiencing optimal treatment benefits. They have to contend with regular and often long trips to health facilities, taking tablets large in number and size, as well as bearing drug side effects which present differently for each of them. HIV treatment also occasions feelings of suffering, difference, and stigma.

Many youths struggle with the tension between concealing and disclosing their serostatus. They have to make the complex consideration between possibly ensuing social support and social devaluation. This leads to situations wherein medication is anxiously hidden or treatment is not adhered to. This does not only have important physical consequences but equally compounds the mental and social burden of HIV. When the serostatus or treatment are accidentally discovered and unveiled by others, it often has life-altering consequences for these youths. So even with effective treatment at hand that helps to evade or diminish the health consequences, living with HIV continues to be fraught with difficulty.

This means that both accessible ART and the perceived convenience of accessing ART are for these youths key to experiencing healthy lives. Their environments – including social networks and health professionals, among others – play a crucial role in rendering ART convenient and in supporting treatment adherence. It often requires persuasive and persistent outreaching efforts to make youths benefit from treatment. When the health impact of HIV is contained through this treatment, it has a ripple effect in other life domains. It increases the youths' hope and gives them a more positive future outlook, which further facilitates their active participation in all spheres of public life.

“After discovering my status, I was like an animal that is sick. When tied on a tree, it does not enjoy itself. It cannot eat and it remains there, so it cannot enjoy life to its satisfaction. One thinks of death at all times, and if you ask for any assistance, you are told that you are useless and you will die anytime, after all. People can read or hear about HIV, but they do not understand it. Instead of giving advice, more pain is inflicted, like when they say ‘go and commit suicide’, ‘go to hell’ and so on. For me, even if you tell me ‘go to hell’ jokingly, I cry because I fear death, knowing that it is close to me.”

Suzan, 16-year-old girl





“Many people with HIV do not get good advice. You are only told that you have HIV and that’s that. One then starts thinking what life will be like. ‘I will die without producing a child.’ People do not receive proper counselling. Some people we meet discourage us when we disclose our status. They tell us we are finished and we are candidates of the grave. This causes us to wander off. We should be selective on whom we disclose to.”

Dagie, 17-year-old boy

“If you find out that you are HIV-positive, you feel bad. You start to feel sorrowful to the point of thinking about throwing the medicine away. I would also like to feel light enough and enjoy myself like all the others, but I feel heavy. I see that people are very free but I am not. I have strict guidelines on treatment, eating, and hospital visits, which are heavy burdens in my life.”

Angella, 16-year-old girl





“This picture shows the medicine I have been swallowing for a long time, along with the water I use to take it. This medicine has become my daily food, like the one talked about in the prayer, Our Father. It shows that before I do anything on my day’s programme, it is the medicine that I have to see first and make sure I have swallowed it. If this was a full plate of my favourite food, everyone would be envious. Instead of people being envious of me, they stigmatise me because of this daily menu.”

Dagie, 17-year-old boy

“I always pass here when going to the health centre, but each time I fear that these rotting pieces of wood will break and I will fall into the stream, just like I fear that people will one day discover my HIV status as I interact with them.”

Inbox, 19-year-old boy





“I used to carry my drugs from the clinic in the tins, as others would leave the tins at the clinic, until a boy on the street told me that my ‘big drug’ [antiretroviral medicines] was making noise and scaring him. I really do not know how he discovered that I had HIV drugs in the tins. I felt very bad that people can identify us wherever we are.”

Angella, 16-year-old girl

“This is what should be included on a girl’s table. We put things like jelly on it, but this table is hiding something, and that is our HIV medicine. So on this table I put all my essentials except one, my ARVs. I cannot risk putting them there because someone can get into my room and see it. That can then become the talk in the village. I fear walking on the streets when everyone is aware of my condition.”

Small, 17-year-old girl





“At times the situation can get really bad and a person with HIV sees that people who should be helping, are putting stress on him. My teacher saw me at the ART clinic and later disclosed to my classmates that I am HIV-positive and on drugs. I felt very bad and I tried to drown in this pond but it was too shallow. After this attempt, an inner voice told me to be strong. I will never forgive that teacher in my life.”

Josh, 18-year-old boy