# The Forgotten Generation: young people born with HIV in Malawi

Some 200 young Malawians are tightly packed onto benches, leaving two girls and two boys standing in the middle wide-eyed and apprehensive. One of the girls, not a day older than 15, is shifting nervously from foot to foot. The four are newcomers to Tisungane teen club. After introducing themselves, two hundred teens descend to give them a hug or a jovial slap on the back. Smiles erupt onto their faces. These four have taken the first step in getting the support they need living as teenagers with the human immunodeficiency virus (HIV) in Malawi.

Tisungane Clinic’s teen club in Zomba Central Hospital is one of many throughout Malawi that support HIV positive adolescents. These clubs are a lifeline for teens – mostly between the ages of 10 and 19 – who are not only dealing with the physical, emotional, and sexual changes of adolescence, but are also learning for the first time that they have been lied to their whole lives about a disease that leaves them feeling stigmatized and alone. However, hope remains as the teen clubs provide the space for acceptance and healing.

**HIV in Adolescents**

According to [UNICEF](http://data.unicef.org/hiv-aids/adolescents-young-people.html), the leading cause of death in Africa of people aged 15-19 is AIDS (caused by HIV). Despite a decline in HIV in the general Malawian population from nearly 12 percent in 2004 to just over 10.5 percent in 2010, the prevalence rate among adolescents has actually increased in 15-19 year olds. In 2013, the Malawian Ministry of Health estimated that 4.2 percent of girls and 1.3 percent of boys were living with HIV. This translates to approximately 93,000 adolescents living with the disease with nearly 7,000 HIV-related deaths among teens that year.

**The forgotten ones**

Among this group is the cohort of children who simply missed out on today’s successful and widely promoted “prevention of mother to child transmission” (PMTCT) programs. These programs stop HIV positive mothers from passing the virus to their babies either in utero, during birth, or while breastfeeding.

However, in the late 1990s and early 2000s, these programs didn’t exist. Even just before 2011, anti-retroviral drugs (ARVs), or anti-HIV medicines, were only given to pregnant women with a low number of CD4 cells – helper cells that fight infection. In 2011, Malawi pioneered [Option B+](http://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/malawi), offering lifelong ARVs to all HIV positive pregnant women regardless of CD4 count. In 2013, nearly 80 percent of HIV positive mothers in Malawi were receiving ARVs; this is in stark contrast to 2009 when less than 20% received the drugs. Consequently, HIV transmission rates between mother to child have fallen dramatically.

Option B+ is a huge success that has now been adopted by most countries in sub-Saharan Africa. In the shadows, however, are the children that were born to HIV positive mothers before services were available. These children are now coming of age, learning not only that they are HIV positive for the first time, but that they have been deceived by the adults they trusted.

**“I’m better off dead than alive”**

Phalyce Jailos is 18 years old and has HIV. She’s been living with the disease since she was born, but it wasn’t until she was 12 years old that she learned about her condition. “I was 12 and taking medicine every day but my mom didn’t tell me why. [One day] I overheard it at the hospital,” says Phalyce. After Phaylce learned of her status, she tried to kill herself by ingesting a full bottle of her HIV medication. She felt hopeless, lied to by her own family, and without the support she needed to keep living.

Phalyce’s story is not uncommon. Violet Banda, another young person living with HIV in Malawi, was told by her family that she was taking medicine (actually HIV medication) for “energy”. Violet found out her status after secretly reading her hospital file when she was 14. “It was very difficult. I defaulted on my medicine.” Violet reflects, “There wasn’t a proper way to tell me [about my HIV status]. Maybe they [the guardians] were afraid.” Maria (surname withheld), 21, recalls when she was 17 and found out her seven HIV negative older siblings had hidden her HIV positive status from her, “I kept thinking, I am better off dead than alive.”

**A ray of hope**

What pulled these teens away from the brink of hopelessness was the sense of community they found through teen clubs and support groups for young people living with HIV.

Tiwale means “shining star” in Chichewa, one of the local languages of Malawi. Similar to Tisungane Clinic and teen club in Zomba, Tiwale Clinic and teen club operates every second Saturday at Bwaila Hospital in Lilongwe. More than 430 HIV positive young people from ages 10 to 20 attend clinical visits to receive medicine without the throngs of adults present on weekdays. This privacy is important to young people. “If teens go to the adult clinic, they feel shy. They can even cry on the queue,” says 23 year old Rejoice Chisinga, a teen club peer support leader.

Both Tiwale and Tisungane clinic began after clinicians noticed how many adolescents stopped taking their medicine, also known as defaulting. This puts their lives in danger as HIV can quickly destroy the immune system and mutate, leading to drug resistance. According to the Guidelines for the Use of ARVs in Pediatric HIV Infection, poor adherence among adolescents may be due to a number of factors, including side effects, frequency of dosing, or psychosocial reasons. Many teens default on their medicine after the shock of learning they are HIV positive. “I was weeping when I found out, confused, and crying. I stopped taking the medicine. Without Tiwale, I would have been dead,” says Maria. For HIV positive teens in boarding school, it may be a question of how best to hide taking their medication when confronted with frequent doses. “My friends didn’t know. I used different pill bags and told them it was for asthma,” says Maria. For these reasons, teen clubs continue to focus on the importance of adhering to medicine.

In addition to clinical assessments, teens attend sessions on life skills and receive psychosocial support. Baylor University began one of the first adolescent clubs in 2006 at their clinic near Kamuzu Central Hospital and currently has approximately 800 teens enrolled. According to Judith Lungu, Special Project and Training Coordinator at Baylor, “For a long time there have been adult HIV programs and the adolescent group has been more neglected.” Simon Mtambo, Teen Club Coordinator at Baylor, adds, “There is a power [for these teens] in just knowing another adolescent that is HIV positive.”

The one precondition to entry in the clubs is that teens must know their status. However, disclosure in the community is still a hurdle for most teens as stigma is a painful reality. At 14, Innocencia Mpinda told her best friend of her status. Now 18, she remembers how she felt after her friend spread the news: “I didn’t want to go back because I was ashamed. I relocated to another school.” Twenty-one year old Tionge (name change) recalls a similar incident with a friend when she was 14: “People are not educated enough”.

According to [UNICEF](http://www.unicef.org/malawi/children.html), there are half a million children orphaned by AIDS in Malawi. Teen clubs provide a supportive adult network that can step in during cases of discrimination from guardians. Innocencia was being raised by her grandparents and experiencing discrimination. “He (my grandfather) wouldn’t eat my food, not touch my property,” she shares. Staff at Tisungane teen clinic intervened on Innocencia’s behalf.

Nzotheka, meaning “it’s possible” in Chichewa, is a support group for HIV positive youth that meets weekly. Group leader Harrison Chirwa, age 23, comments, “The group is very important. We encourage each other to speak publically.” Group member Marcus Yamikani Kumbikano, age 20, grew up in an orphanage and learned of his HIV positive status when he was 12. He now shares, “You can live a positive life; you can live the life you want.”

**What next?**

Despite the successes of the teen club, Dr. Joe Gumulira, Senior Clinician and focal point for pediatric and adolescent services at Lighthouse Clinic in Kamuzu Central Hospital, worries about the “poverty cocoon” given the majority of teens have lost one or both parents: “How will they fit into society if they don’t have all the jigsaw pieces? Maybe they had to delay school – what next? Did we make them live so long just to experience poverty?”

This cry for education and career development is also voiced by the teens. Harrison Chirwa concurs, “Most people don’t have biological parents. They don’t have school fees and many can’t finish tertiary education. We need more educated people living with HIV.”

Yanjanani Magaleta, whose name means “unity”, lost both parents at a young age. Her lifelong dream is to be a nurse. Although admitted to nursing school last year, Yanjanani, age 21, has struggled to meet tuition fees. “Girls must be encouraged to go to school, to depend on themselves,” she says. As one member of Nzotheka echoes, “Train the youth so they can help themselves. Let us stand on our own.”

Despite these challenges, teens find support in the clubs and fellow members. Maria explains, “When not in teen club, I was living a life of stress, very alone. My new life is much better. I can disclose freely, be encouraged by my friends. We are people taking the same drugs.” Innocencia Mpinda shares, “I’ve accepted it [my status] and nothing can change. I can do anything on my own.”