

Pamoja Tuwalee

Success story: Layers of support for Steven and his caretakers

Steven Abdul* is a 15-year-old boy who lives in the outskirts of Tanga, a port city in Tanzania. Although he spent most of his childhood in and out of hospitals, Steven's spirits are now high as he talks about his dreams to be an actor.

When Steven's mother, Pendo, passed away, Steven was only about four years old. They were living in a different district outside of Tanga at the time. Although the cause of Pendo's death was officially ruled as "unknown," Steven's grandmother, Mary, suspected that her daughter was HIV-positive. Furthermore, she believed Pendo passed the virus on to Steven because she never received any preventing mother-to-child transmission education.

After the burial, Mary and her husband knew they had to bring the newly-orphaned Steven to their home and become his primary caretakers. Unfortunately, almost immediately after bringing him home, they realized he had serious health issues of his own. He began fainting, and sometimes he would faint as often as three times in one day.

Steven was admitted to Bombo Hospital. After many tests and examinations, the doctors could not determine the reason for Steven's fainting spells. Their next step was to give Steven a blood transfusion. Although his health improved slightly, his grandparents were not fully satisfied with the tests and treatment plans at Bombo Hospital. In the back of their minds, they knew he had to be tested for HIV/AIDS.

At that time, the medical officers at Bombo Hospital never suspected nor tested Steven for HIV/AIDS because the official cause of his mother's death was unknown. In addition, the only major health issue Steven presented was random fainting episodes. Therefore, they treated Steven for fainting and any other health issue that would arise, but over the years, they never tested for HIV.

After a few years, Steven's grandparents were frustrated that their grandson continued to get sick. They both decided to take him to a new hospital. They wanted to demand that the doctors test him for HIV.

When Steven was 11, he was diagnosed as HIV-positive by medical officers at Ngamiani Hospital. In addition, they discovered he also had tuberculosis (TB). Immediately, they started him on the TB treatment. After completing the six-month TB treatment regimen, Steven was referred back to Bombo Hospital to begin antiretroviral therapy (ART). Finally, Steven's health began to improve.

Although Steven was finally receiving the medical treatment he needed, the problems in his household did not end. The grandparents had difficulties providing enough income for the household's basic needs, Steven's school fees, and all of his medical expenses. In addition, this was the first time the grandparents had to take care of an HIV-positive dependent and that made them nervous.



The ACT Officer, Mary, Steven, and Ntandai at Steven's home.

Fortunately, Pamoja Tuwalee team member, Ntandai, met Steven and Mary during community outreach. In addition to his position as a Most Vulnerable Children Committee member, Ntandai is also a member of the Bombo Hospital Health Committee.

Mary explains how grateful she is for Ntandai and Pamoja Tuwalee by describing the wealth of information she receives from him and the project, "Ntandai has been so helpful and so supportive because of the knowledge he is giving to us when we go to the clinic. We learn about health, nutrition for [HIV-positive] children like Steven, and the knowledge on how to take care of an [HIV-positive] child, specifically about preventing transmission to other members of the household. Without that education, we may not be living well like this."

"On top of that, the health fee exemption card is a blessing to my family. Steven used to get sick so often, but I would not have enough money for health fees or transportation. But now, even when I am away traveling, Steven can take his card, go to the health facility, and receive health services for free," Mary adds.

Health Fee Exemption Cards (HFECs) are identification cards for most vulnerable children (MVC). They are the direct results from Bantwana's advocacy efforts through Pamoja Tuwalee. Without these cards, MVC and their households would be required to pay fees at the health facilities. If they show at the facility and cannot afford the fees, they would likely be turned away. However now, with the HFEC, identified MVC are able to receive free health services. Council-level key decision makers and Local Government Authorities have prioritized MVC and their access to health care, and Councils now budget and pay for HFECs for MVCs in their districts.

In addition to consistent education and the health fee exemption card, the family is also linked to other Pamoja Tuwalee supports. At school, Steven is a part of a Child Rights Club (CRC). Because of the CRC, he has a supportive group of friends and an opportunity to learn about his rights and responsibilities as a child. In addition, the CRC Matron has personally taken responsibility to watch over Steven. She gives him additional fruits and vegetables from the CRC garden to ensure he has enough food to eat while taking his ARVs, and she encourages him both in school and out of school.

Child Rights Clubs are safe spaces where children come together to learn about their rights and responsibilities. CRCs emphasize child leadership and implement child-led approaches. Therefore, clubs are led by Pamoja Tuwalee-trained child members with guidance from Bantwana's Child Protection Booklet and supervision by adult Patron or Matrons. Underpinning the CRC platform is the assertion that children have a right to be heard and be taken seriously, to participate in decision-making, and to express their views on matters that affect their lives. In addition, CRC leadership deliver HIV/AIDS sensitization and education through discussions and activities. Members share their experiences and messages with the community through theatre, dance, and songs with social messages.

Steven's school has also hosted a Pamoja Tuwalee Community Nutrition Assessment and Education (CNAE) session. At CNAE, Steven was identified by an Accelerating Children on Treatment (ACT) Officer as an HIV-positive child. In order to ensure Steven is receiving proper treatment, the ACT Officer regularly follow-ups on him. She even visits Steven's home to check on his living conditions, ensures he is adhering to ART, and provides any other counseling or support for Steven and his grandparents. This ACT Officer has even accompanied Steven to the health facility for additional appointments if and when he feels sick.

Community Nutrition Assessment and Education sessions utilize national nutrition assessment counseling and support materials and are conducted by Pamoja Tuwalee-trained CNAE team members. In addition to assessing children's nutritional statuses and providing nutrition education to caregivers, CNAE team members also provide coordinated multi-sectoral support through referrals, including HIV testing and counseling. CNAE also support ACT interventions through the integration of mobile Voluntary Counseling and Testing and HIV education, enabling onsite management of HIV referrals.

The household also received household goods from a Pamoja Tuwalee savings group, LIMCA, when they were in dire need. The savings group members created a most vulnerable children fund as a part of their LIMCA group. After hearing about Steven and his grandparents, they donated food and soap to the family. The plans are now in place to start a LIMCA savings and lending group in Mary's community so that she and others will be able to save and borrow money themselves.

Because of the various layers of Pamoja Tuwalee support, Steven and his grandparents are progressing positively. Steven and his grandmother smile as Steven discusses his love for drama at the CRCs and his dreams of being a role model and actor in the future.



Steven showing off his Health Fee Exemption Card.