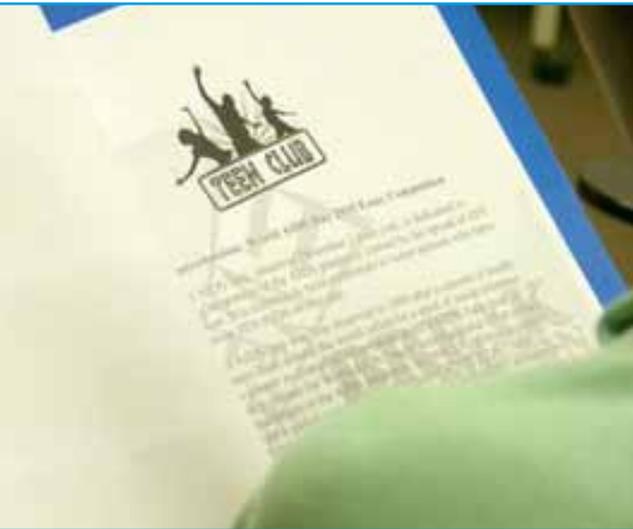


Children and AIDS Regional Initiative

BOTSWANA TEEN CLUB

When HIV and adolescence collide, a teen club teaches courage

Gaborone, Botswana – A first kiss for teenagers is often awkward but heavily romanticized in the recounting. Refilwe*, an energetically cheerful and pretty 18-year-old, tells a painful story of trust betrayed.



She was at a family party when a boy similar in age to Refilwe told her he liked her and kissed her. In her excitement, she told her cousin, one of the few people she had trusted with the news of her HIV status. The next thing she remembers, the boy's mother was shouting at her and accusing her of spreading her HIV germs to her son. Refilwe heard from another cousin about the boy's mother's reaction.

“One of the hardest aspects is thinking you have someone you can trust and then to be stabbed in the back,” says Refilwe, who has just finished high school in Gaborone, Botswana. Refilwe tested positive for HIV infection when she was 11. At the time, she had been in and out of hospital for a few years. She was eventually diagnosed with tuberculosis and tested for HIV. Soon after, her mother was tested for the first time. She too was positive.

Refilwe is one of an estimated 2,000 teenagers in Botswana too old to have participated in the country's massive scaling up of

**Name changed for privacy purposes*



The Children and AIDS Regional Initiative has been supported by the Australian and British governments. It is part of a five-year collaboration to mitigate the impact of HIV in southern Africa and to develop social protection systems in the region by focusing on vulnerable children and those affected by HIV and AIDS. The six DFID-supported CARI programmes work in HIV hyper-endemic countries (South Africa, Lesotho, Botswana, Swaziland, Namibia) plus one with relatively lower rates but rapidly rising 'hot spots' (Angola). The three AusAID-supported CARI countries also work in high HIV prevalence countries, linked to chronic food and economic insecurity. All nine countries contend with issues of pervasive social and economic inequalities, extensive migration and human development challenges. The current global economic crisis has exacerbated these. The programme provides a valuable regional analysis of how HIV is impacting on child poverty and on national capacities to deliver social development and a broader response to chronic poverty.

services to prevent mother- to-child transmission (PMTCT) of HIV, which it started in 1999. Since then, Botswana, the first country in the region to realize a wide scale-up of PMTCT services and the first country in sub-Saharan Africa to reach a greater than 80 per cent coverage of PMTCT services, has seen a reduction of deaths among children younger than five years. The PMTCT scheme has more than 90 per cent coverage rate now and aims to reduce the risk to less than one per cent of children infected during pregnancy, delivery or breastfeeding.

HIV and teenagers and stigma

For teenagers like Refilwe who discover their HIV status when entering adolescence, the issues of disclosure, coming to terms with that status and learning how to cope with a daily regime of medicine for life can be tough – on top of the typical teenager trials and tribulations.

Even in a country such as Botswana, which has one of the world’s highest prevalence rates, at 25 per cent, and 12,000 to 20,000 children who are HIV-positive, the stigma, discrimination and fear of HIV remain acute.

Government estimates expect more than 4,000 teenagers will need antiretroviral (ARV) treatment, treatment that helps prevent the virus from multiplying inside the body, in the next year or two.

“I don’t blame people for being scared of HIV. It scares me and I can understand that,” says Refilwe. “Nobody would wish to have this virus and be linked to a life-long disease.”

Refilwe moved out of her aunt’s house, where she had moved when her mother went to work in South Africa, not long before the first-kiss incident. Now she lives alone in a small cottage, unusual for anyone in this African country, let alone a young woman. But she feels living apart from her extended family at least allows her the freedom to grow up in peace. “I feel guilty, yet I did not bring this on myself. HIV is not my fault.”

Speaking up for other teens

She also is taking on the stigma, speaking out to break down people’s fears of the disease. She recently addressed a room full of Rotarians, a group of Gaborone’s business establishment. Refilwe says her confidence to speak up was boosted through her participation in a teen club for HIV-positive adolescents.

The Botswana-Baylor Children’s Clinical Centre of Excellence, which opened in 2003 to focus on the expanding paediatric treatment, started the teen club in 2005 to tackle the growing number of HIV-positive teenagers who need emotional and psychological support as well as medical treatment.

“The teen club is so important. Instead of reminding you that you are HIV-positive, it does just the opposite. It makes you forget about HIV and makes you feel happy about life and seeing peers who share the same experiences that you do,” explains Refilwe, who dedicates much of her free time to speaking at public events as the voice of teens living with HIV and explaining the need to expand the work of the club.

FAST FACTS

- HIV prevalence among adults appears to have stabilized, but remains high
- Nearly all pregnant women receive the support of a skilled attendant at delivery, though some of the poorest miss out.
- Overall, HIV testing among pregnant women has remained high since 2005;
- Nearly all mothers and infants receive regimens to prevent HIV infections in children.
- There is remarkable progress toward the standard use of higher quality PMTCT regimens and treatment for HIV-positive pregnant women.

Source: Botswana PMTCT fact sheet, available at http://www.childinfo.org/hiv_aids_factsheets.html



Teenagers spend Saturday morning at the Centre where they engage in different activities. This week, students are working on writing essays around living HIV positive and what it means to them.

The club is also demonstrating the huge gap in coverage of HIV and AIDS treatments for adolescents, says Dr Michael Tolle, Associate Director of the Botswana-Baylor Centre. "For many years, the treatment of children lagged behind, and there was a huge need to develop specific paediatric treatment. Now, as more children survive and live longer, we need to cater to this group of adolescents who are dealing with their own set of issues and are also physically in transition."

Teen clubs

Some 200 teenagers aged 13 to 19 gather in front of the Botswana-Baylor Centre for warm-up games on the last Saturday of every month, just next to the country's primary public hospital. A 16-year-old boy, who has not told anyone outside the club of his HIV status, leads the crowd of teens in sneakers and jeans.

Sam (not his real name) says he figured out he was infected after watching a public service announcement on ARV treatment three years ago. His aunt, who raised him after his parents died, had been reluctant to tell him until he was old enough to understand. The knowledge left him lonely and angry, he says. The teen club meetings helped him find friends and confidence. He is one of ten teen leaders elected for a year to guide the activities and represent the other teens on how the club should work.

Five volunteers in their early twenties, who are a mix of foreign university students and local Botswana professionals, direct the club's activities, ranging from essay writing to swimming. One of them, Wetshe Maskowe, a fourth-year social work student at the University of Botswana, believes the experience with the teenagers has opened her eyes and her mind. "They face many problems," she explains. "Adherence is a big problem. Some forget but many don't want to take their pills every day." The other major issue is linked to disclosure and dating. "How do you tell someone, especially if you like them, you are HIV positive?"

The Baylor approach, explains Dr Tolle, believes children have the right to know of their status from the start to avoid the shock of learning about it years later. They teach children about the medication early and correlate their C4D count to soldiers fighting their immune systems. He says many caregivers, however, are still hesitant and fear that younger children are not capable of understanding.

The link between disclosure and treatment adherence

Dr Tolle believes that disclosure and adherence are closely linked. "One of the challenges adolescents face is maintaining good (health) care, especially around their psychological wellbeing. Depression can make their adherence less than optimal, so having a support network that knows their status can be critical to how well they are doing physically."



With the success of the teen club, efforts are underway to expand them to different parts of the country. They are receiving guidance from the Botswana Baylor Centre and financial support from Barclays and UNICEF through funds provided by UK Aid.

The concept of the teen club is expanding, with five clubs now newly set up in hospitals in other towns through community groups with guidance from the Botswana-Baylor Centre and financial support from Barclays Bank and UNICEF, through funds provided by UK Aid from the Department for International Development.

The teen club experience is also helping to inform government efforts to create services for adolescents. "The health system feels comfortable with children under five years and adults," says Doreen Mulenga, UNICEF Botswana Representative. "There is not much knowledge about and few services catering to teenagers' needs," she says. UNICEF is working with the government, experts from the Botswana-Baylor Centre and partners to find a strategy for ensuring adequate care and support for HIV-positive teenagers.

"My hope is that the experience we are learning from Baylor will become part of the public health system and part and parcel of response, says Dr. Haruna Jabril, National Paediatric Advisor for the Department of HIV and AIDS within the Ministry of Health. "Now with few children being born positive and falling into the pool, we have to cater to those teenagers who are growing up. We need a national care package for adolescents that spells out the types of treatment they need and reduces drug resistance as well as provides for their psycho-social wellbeing."

"When I first came here," Refilwe recalls, "I saw people being cheerful and happy. I love joking around, so it put me in an environment where I can freely express myself. Being a leader was a first for me and because I was living to motivate people and saw their level of confidence in me, I really saw the potential of having a safe environment for young people like me to interact and feel that we were not alone."

Shantha Bloemen, February 2011

Photographs © UNICEF/Diane Tipping Wood



There are an estimated 2,000 teenagers in Botswana too old to have participated in the country's massive scaling up of services to prevent mother-to-child transmission of HIV, which started in 1999.

UNICEF ESARO, Nairobi, Kenya. Tel: +254 20 7622224. E-mail: ESARO_UNICEF/RO/ESAR/UNICEF@unicef.org.
Website: <http://www.unicef.org/esaro/>



Australian Government
AusAID



UKaid
from the Department for
International Development

