Botswana : Fun for positive teens at their own club

- Orphelins du sida, orphelins et enfants vulnérables (OEV) -
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Gaborone, 3 November 2009 (PLUSNEWS) - Raging hormones, peer pressure and coming to terms with a changing body image - growing up is difficult enough without the added burden of living with HIV, and keeping it hidden from friends and classmates.

"Being a teenager is very hard ; you have to keep up with the changing life, do what the others do," agreed Katlego Lally*, 17, in Botswana's capital, Gaborone, who was born with HIV but only learned of her status six years ago. "My school friends don't know ; if you bring up HIV they're quite ignorant."

As one of the first countries in southern Africa to start rolling out a national antiretroviral (ARV) treatment programme that now reaches nearly 100 percent of those who need the medication, Botswana has a rapidly growing population of children infected at birth who are surviving into adolescence.

Simply referring these teenagers to adult clinics and ignoring their special needs could lead to a reversal in the gains Botswana has made in combating HIV, argues Ed Pettitt, coordinator of the Teen Club programme at the Botswana-Baylor Children's Clinic Centre of Excellence in Gaborone.

"Adolescence, as a period of development, has the highest risk for therapeutic failure - not just for ARVs, but any medication for a chronic illness," he told IRIN/PlusNews.

"I call it the 'inconvenient truth' of paediatric HIV - it's great that you can put children on ARVs, but you have to realize that one day they're going to grow up and become teenagers, and all the challenges and headaches that come with adolescence are going to impact on their behaviours."

Julia Rosebush, a doctor at the Children's Clinic, which provides care and treatment to HIV-infected infants and children through a partnership between the Baylor International Pediatric AIDS Initiative and the Botswana government, has already seen how teenage rebellion can translate into treatment failure. "A lot of kids throw away their pills - we're finding a lot who are failing first-line treatment already."

Pettitt said only three lines of drugs for treating HIV were available in Botswana, and if interrupted treatment caused resistance to these to develop during adolescence, "your long-term prognosis doesn't look good".

A whole new world

The first Teen Club started in Gaborone in 2005 with just 23 teenagers, but now has over 400 ; that number is expected to reach over 1,000 by 2012, and five satellite clubs have launched in other parts of the country.

Clinic staff and some of the older teenagers who serve as "teen leaders" run monthly events at the clubs, providing support and sanctuary to the vast majority of members who have never disclosed their status to anyone besides their caregivers.

"When there's only one other person that knows their status, they're leading kind of double lives," said Pettitt. "They can't even tell their best friend because they fear that friend will tell others, and they'll never be able to go back to school."

For Lally, who started coming to Teen Club last year, realizing that there were other teenagers like her was life

changing. "I was just living in a dark tunnel, waiting for the day I would die," she said. "The doctor I was seeing told me about Teen Club and I saw a whole new world ... I thought it was just me, but I saw a whole lot of excited and happy teenagers."

She is now a teen leader and thinks of her friends at the club as "like my family". "Everyone is open with each other, because when you're in the same situation you understand each other," she said. Mostly they talk about "normal teen stuff" rather than their HIV status.

The monthly events are usually focused on fun and general life skills rather than HIV-related issues. Past activities have included pool parties, salsa classes and movie nights, although the most recent event focused on how to disclose one's status to friends and family.

After a panel discussion in which several adults and one teen leader shared their experiences of disclosure, the teenagers broke into small groups to act out skits where they practised disclosing to best friends, girlfriends, teachers and cousins.

Sexuality and relationships are particularly fraught for HIV-positive teenagers, but giving them tools for disclosing to romantic partners is vital if they are to use prevention methods, said Pettitt.

Mpho Mosala*, 17, another teen leader at the Gaborone Teen Club, has been dating the same girl at his school for the past two years but he has yet to tell her of his status. "Right now, I don't think it's so important because we're not doing anything that would expose her," he said. Lally has decided to stay "out of the dating mode", at least until she finishes school.

While younger club members attended the session on disclosure, older teenagers were busy clearing undergrowth from a plot across the street where a drop-in centre for HIV-positive adolescents is to be built. They were joined by volunteers from Barclays Bank, which contributes part of the funding for the programme as well as financial literacy training to the teenagers.

The centre will provide a much needed place where teenagers and their caregivers can come between clinic appointments and monthly events for counselling, training and sports, or just to hang out.

Model programme

The success of Botswana's ARV programme and its prevention of mother-to-child transmission (PMTCT) programme means that while the number of infants born with HIV is dwindling, the number of HIV-positive adolescents is growing every year. "In three or four years we'll pretty much be an adolescent clinic," said Pettitt.

Recognizing the growing need, Botswana's Ministry of Health is partnering with Baylor to develop an adolescent care package to train health care workers at government ARV clinics in how to cater for teenage patients.

While Botswana is slightly ahead of the curve, other countries in the region are also dealing with growing numbers of HIV-positive adolescents and looking for models they can adapt.

Baylor has launched similar clubs attached to its Children's Clinics in Swaziland, Lesotho, Malawi and Uganda, and a number of other countries and organizations have requested materials on adolescent care and support.

Pettitt welcomes the interest, saying : "A lot more attention and resources needs to be put towards finding ways to keep adolescents adherent and prevent them from infecting others."

*Not their real names