



A TASO client, aged 19, who recently gave birth

## Sexuality of young people perinatally infected with HIV

### A neglected element in HIV/AIDS programming in Uganda

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In HIV/AIDS treatment, care and support programming, concern for the vulnerability of young people to HIV infection tends to overwhelm some of the more positive realities of sexuality, which is an equally important part of growing up.<sup>1-2</sup> In Uganda and elsewhere in sub-Saharan Africa, wide programmatic gaps exist in addressing sexual and reproductive health needs of young people perinatally infected with HIV who are now growing into adolescents and adults. The almost exclusive focus on the negative implications of HIV tends to hinder initiation of programmes aimed at addressing the sexual desires of young people living with HIV. This problem is compounded by the false assumption that young people (10-19 years) living with HIV in Africa may be too few to justify targeted programming and a reluctance to acknowledge that it is natural for them to have sexual needs and desires and to act upon them. Many young people living with HIV aspire to be just like their peers who are HIV negative. Therefore, it can only be anticipated that these young people as well desire to explore their sexuality and appreciate the opportunity to talk and ask questions about it.

Whereas it was never previously anticipated that infants born with HIV would have the opportunity to live on to adulthood and develop sexual desires, the roll-out of antiretroviral treatment programmes seems to have made this possible. While exact numbers of young people aged 10-19 years, perinatally infected with HIV are not easily available, indications from HIV/AIDS treatment, care and support centres in Uganda show a small but steadily growing population. For instance, TASO Uganda's oldest surviving perinatally infected client turned 23 in 2006. TASO (The AIDS Support Organization) has also recorded some 5000 young people living with HIV since infancy. The Pediatric Infectious Disease Clinic (PIDC) in Mulago Hospital in Uganda has over 600 young people living with HIV between the ages of 10-19 years and The Mildmay Centre is attending to a similar number.

These girls and boys are now beginning to explore their sexuality; they are dating, with some sharing intimacy. By 2006, TASO had cumulatively recorded 184

pregnancies, PIDC nine, and The Mildmay Centre seven among young women receiving HIV/AIDS treatment, care and support. Health-care providers at these organizations suspect that more young women are likely to become pregnant, though it is unclear whether these pregnancies are intended/unintended or wanted or unwanted. What seems clear is that growing up with HIV has not significantly affected attitudes towards childbearing in Uganda. The desire to have children early in adult life may be high also among some HIV-positive young people. In a recently completed TASO Uganda/Population Council survey involving 732 young people with HIV aged 15-19 years, 90% of the boys and 87% of the girls expressed a strong desire to have children in future. It can only be suspected that young people living with HIV may succumb to familial and social pressure to have children early so that they do not die without offspring. Unfortunately, existing HIV care and support programmes do not seem to address the fertility aspirations or desires of this small but rapidly growing population of young people.



Photo: WHO / www.AVERT.org

## Opening discussions around sexuality

The difficulties of working with young people in general on issues of sexuality become more complex in the case of young people living with HIV. If at all sexuality is discussed during counselling, it tends to be on discouragement of sexual initiation. In a recent clinic-based study, one of the young people living with HIV lamented that: *“If you say HIV-infected people should abstain, it’s like condemning us to die.”*<sup>3</sup> Clearly, sexuality is central in the lives of these young people – it seems to be a source of happiness, personal fulfilment and well-being. However, service providers and parents/guardians seem neither interested, motivated nor prepared to find out about young people’s sexual desires.

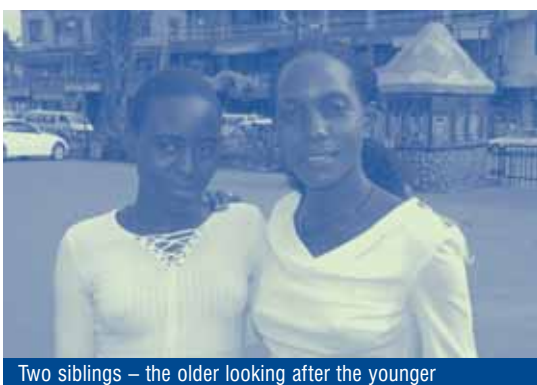
It is clear from the preliminary results of the TASO Uganda/Population Council study cited above that most parents/guardians of young people living with HIV face dilemmas in opening discussions around sexuality issues with them. One parent stated thus: *“What do*

**Existing HIV care and support programmes do not seem to address the fertility aspirations or desires of the rapidly growing population of young people living with HIV**

*I tell her? Not see someone? I would certainly like to see that somebody appreciates and accepts her. I want her to be happy. Part of me is worried about her being rejected and what they do in relationships. So it’s just as well that we do not discuss it.”* Many young people living with HIV are also hesitant to share intimate aspects of their lives with their counsellors or even parents/guardians who often seem to assess them for their sexual risk behaviours and normally preach against sexual relationships.

## Addressing young people’s real concerns

Even though HIV/AIDS programmes promote the concept of positive living, issues stressed include



Two siblings – the older looking after the younger

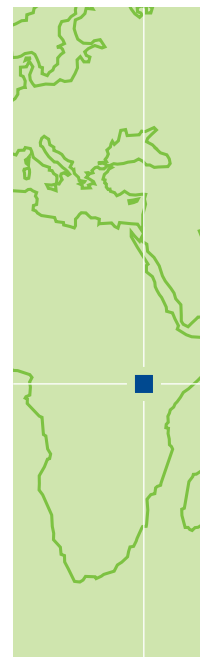
proper nutrition, exercise and controlling stress. Talking about positive living without embracing issues of sexuality has often left most young clients unprepared for satisfying sexual lives; and worse, it may encourage non-disclosure of their HIV status to potential and existing partners. In the TASO Uganda and Population Council study, over 60 percent of girls and boys in relationships have never disclosed their HIV serostatus to their current partners. Yet, as found, 39% of these young people are in a discordant relationship.

Contrary to the common assumption that young people living with HIV are asexual or should be asexual, the survey reveals that many of these young people are dating (52%) and some are sexually active (34%). These young people do not construct their lives around illness. The majority (about 70% of them) are not the least worried about being HIV positive because this is a condition they have lived with since infancy. Their real concerns are constructed around their looks, finding a date of choice and not being able to express their love fully; as stated by one informant: *“What a burden to love and never being able to experience and receive it back in its fullest.”* While the majority of our respondents saw no reason why people living with HIV should not have sex, many (50%) expressed fears/worries about having sex since this came with a lot of guilty consciousness about infecting another person with HIV and becoming pregnant or impregnating someone. Generally, these young people have big dreams and would like to construct their lives positively. They desire to further their education, dream of getting married and have their own homes in future.

## Empowering young people living with HIV

Currently, HIV/AIDS care in Uganda and elsewhere in sub-Saharan African countries is mainly organized around paediatric and adult care. Most young people living with HIV receive their treatment, care and support through paediatric care clinics while a few receive services through adult care clinics. Either way, the tendency has been to handle young people living with HIV as if they were children. While some service outlets have incorporated child counselling into their treatment, care and support package, this falls short of tackling sexuality issues let alone empowering young people living with HIV with the necessary information to enable them to balance rights and responsibilities, make informed decisions about their lives and contribute to their quality of life in general.

Existing counselling and support packages will need to be updated, reorganized and/or redesigned to 1) address the gap between paediatric and adult care;





Two HIV-positive adolescents fooling around with a researcher

and 2) embrace vital elements of sexuality for young people living with HIV. In order to be effective, interventions will need to address the sexual desires and dreams of young people living with HIV and engage different agencies and groups working with them. Unfortunately, none of the current programmes in Uganda have adequately incorporated these issues. However, TASO, Population Council and World Population Foundation are currently developing

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programmes to address the sexuality concerns of these young people. The programme focuses on:

- increasing access to and use of family planning services for those that are sexually active to prevent unwanted pregnancies;
- improving client-provider communication on sexuality issues by introducing a 'fertility and sexuality desire' assessment tool to be able to systematically screen and refer young people appropriately;
- updating service provider knowledge on sexual and reproductive health needs of young people living with HIV by revising counselling guidelines to streamline family planning and other sexual and reproductive health counselling for HIV-positive adolescents;
- developing a counselling curriculum for HIV-positive adolescents that will be used to strengthen counsellor training and refresh all counsellors on positive adolescent counselling; and
- developing a life skills curriculum for young people living with HIV.

Up till now, treatment, care and support programmes have focused on changing people's behaviour. Emerging evidence from Uganda reinforces the need to

understand and appreciate the private lives of young people perinatally infected with HIV and to actively and meaningfully involve them in the development of programmes drawing on their life experiences. This evidence serves as a concrete basis for generating discussions on how existing programmes will have to change their focus. They need to learn how to provide young people with information and practical support to understand their sexuality as they grow up in order for them to negotiate vital aspects of their sexuality, enjoy positive lifestyles, and avoid undesired consequences such as unwanted pregnancies, infecting others and self re-infection. The possibility of programmes offering value-free information on sexuality to young people living with HIV also has to be debated and addressed. ■

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