Sexual and Reproductive Health and Rights Needs Among Adolescents Living with HIV in Four Southern African Countries

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Background

In 2011, an estimated 4.9 million young people aged 15 to 24 years were known to be living with HIV. Young people account for 40% of all new adult HIV infections.1 As of that year, sub-Saharan Africa was home to 71% of the adults and children newly infected, underscoring the compelling need to strengthen HIV prevention activities in the region.2 Globally, coverage of antiretroviral therapy (ART) is lower among children than adults, yet an increasing number of HIV-positive children are reaching puberty and adolescence. In the drive to scale up HIV treatment, little concerted effort has been made to address gaps between the existing needs of adolescents living with HIV and access to HIV and sexual and reproductive health (SRH) services.

Methodology

A multi-country study on this topic was undertaken, developed and planned jointly by the Southern African AIDS Trust, the Network of African People living with HIV for Southern African Region, the International HIV/AIDS Alliance, and Dignitas International. Implemented in collaboration with local implementing and academic partners, the research aimed to provide evidence to inform current programming strategies and local, regional, and international policies. A second objective was capacity strengthening for regional partners. The study explored psychosocial and SRH needs of adolescents aged 10 to 19 living with HIV in Southern Africa to identify gaps between needs and available SRH and HIV-related initiatives. Funded by the Southern African Development Community (SADC) HIV and AIDS Fund, data were collected across 16 sites in Malawi, Mozambique, Zambia and Zimbabwe, countries with some of the highest prevalence rates among young people in the region. The study design was cross-sectional and observational, using a mixed methods approach, including a situational analysis, semi-structured interviews, focus groups, personal narratives, a Knowledge, Attitude and Practice survey, and direct observations. Data collection took place simultaneously in the four countries between April 2012 and May 2013. A total of 1,977 adolescents and 164 parents, guardians, and health care workers participated. In each study setting, research teams contacted adolescents and their parents through existing ART services and existing programmes working with adolescents living with HIV.

Findings

The findings confirm that social and economic determinants influence the level of SRH and HIV knowledge. Structural factors linked to gender differences, family structure, lower socio-economic status, and living in rural areas are all associated with lower levels of school attendance and less access to health education. Adolescents living outside larger urban centres, specifically girls and those not attending school, have less HIV and SRH knowledge. The sexuality of younger adolescents is often overlooked or ignored. A larger proportion of girls reported having had sex at least once or having a regular partner. This gender difference, combined with negative perceptions about condom use, lack of access to family planning (FP) methods, and low levels of safer sex practices, place adolescent girls at greater risk of contracting sexually transmitted infections, HIV, or unwanted pregnancies.

The study also documents that disclosure of serostatus remains a major concern for adolescents living with HIV. For parents, disclosing their child's serostatus is a delicate and complex process. Many parents and guardians feel ill-equipped to discuss HIV and sexuality with adolescents. Adolescents are often isolated and unable to talk freely about HIV with their friends and families. Taking ART represents a daily challenge for some adolescents, especially when they need to take the medication at school or outside the home.

Once they know they are living with HIV, adolescents face important dilemmas in relation to their sexuality and sexual relationships. While many want to protect themselves and their partners, they often fear that disclosure may lead to a relationship ending. Gender inequities, inter-generational sex, and power imbalances also influence the experiences of living with HIV and require specialised interventions.

Fear of the stigma associated with living with HIV is an important barrier to adolescents' ability to discuss HIV with their peers, families, or health care providers. Within health facilities, adolescents feel that their privacy may not be sufficiently respected or that confidentiality will not be maintained. Adolescents strongly prefer that age-appropriate services be organised. Most adolescents access services situated in either paediatric or adult facilities, especially in smaller facilities outside larger urban centres. SRH services are often not made available to adolescents and they are

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rarely integrated with HIV-related services. Counsellors trained on how to deal with the special issues of adolescents are available in only a few sites offering youth-friendly SRH or HIV services. Some ‘centres of excellence’ have started to focus on adolescent-friendly services and to integrate SRH with HIV/ART services, but such important initiatives remain scarce and under-funded. Adolescent-focused interventions are often short-term and rely on local volunteers to sustain them. There are inadequate communication materials and few trained psychosocial counsellors able to support adolescents living with HIV.

“I have been shouted at and even pinched [...] at first they didn’t tell me why I was taking medication so I reached a point where I got tired; I would miss taking them and my mum would encourage me to take. This other day I took all the bottles and threw them in the toilet...I told her [the nurse] that it’s because I don’t like them, I have been taking them for too long, yet no one is telling why I am taking them. She said: Do you want to die? Do you want your family to start mourning while you are still alive [...] if anyone ever shouts at me again I will stop going there to collect my medication, I will move to another clinic.” - 15 year old boy, Mzuzu, Malawi

Recommendations

Several recommendations are offered based on the research findings. The extent to which they can be implemented will inevitably vary based on the in-country context.

Social and Family Support for Adolescents

- Capacity building and training for families through existing health services and/or nongovernmental organisations should focus on better understanding the needs of adolescents and importance of psychosocial support in addressing the daily challenges of living with HIV.
- Within families, intergenerational communication on living with HIV, safer sex practices, and FP should be encouraged and promoted through the education system and health services.
- Peer support structures and programmes (such as ‘Teen Clubs’) should be promoted in urban and rural settings to provide a safe and neutral social space for adolescents to interact and obtain guidance and counselling as well as peer support.

“I don’t want people to start looking at me differently. My parents are very religious and they won’t understand. It’s already bad at home now because I am pregnant, and telling them I am positive will make it worse.” - 18 year old girl, Lusaka, Zambia

Access to SRH Services for Adolescents

- An integrated approach to SRH and HIV services will strengthen the availability of relevant information, advice, counselling, and safer sex and contraceptive methods for adolescents who are living with HIV as well as access to HIV and/or ART services.
- HIV services for adolescents, particularly at ART clinics, should be provided separately from adult services and in a setting that assures full confidentiality.

- Specialised training for health providers who engage directly with adolescents should be arranged to ensure that their interactions are supportive, positive, accessible, and non-judgemental, and comply with the rights of adolescents to access appropriate SRH services and psychosocial support.
- Helpful messaging, health information, and support for treatment adherence should be disseminated using web-based technologies and mobile phones to scale up access to adolescent-friendly information on sexuality and living with HIV.

SRH Service Provision and Interventions

- Appropriate resources should be identified to provide remuneration for counsellors and peer-educators who are working with adolescents. Reliance on unpaid volunteers to provide specialised adolescent services is not sustainable.
- Multi-purpose funding for adolescent-specific prevention and information campaigns is needed to address HIV-related stigma directed at young people, whether they are living with HIV or not.
- Interventions should avoid a silo approach to meeting the SRH needs of adolescents, and adopt a comprehensive approach that includes livelihoods, health, psychosocial, and education needs.
- Provision of equitable health care for all is essential. Interventions should expand all youth-related health services to rural areas to reach adolescents enrolled at health facilities outside of large urban centres.
- The provision of adolescent-friendly SRH services needs to be located within a gender equitable and rights-based paradigm that will empower all young people to make positive choices and, in particular, will support the rights of girls and young females to exercise informed health and sexual choices.
- Condoms, contraceptives, and safer sex options should be provided through health services in a supportive and confidential setting for all adolescent age groups. Non-judgmental advice should be provided on safer sex options to all adolescents who are sexually active.
- An inter-departmental approach to meeting adolescent SRH needs should include the optimal use of education settings to disseminate extensive and appropriate messages, information, and support for adolescents living with HIV, including ART adherence and information on sexual health, contraception, and FP.