

NEEDS, CHALLENGES & OPPORTUNITIES: ADOLESCENTS AND YOUNG PEOPLE LIVING WITH HIV IN ZAMBIA

FACTS

- The impact of HIV on children in Zambia is significant, with 120,000 infected, and 690,000 AIDS orphans (1), and with improved access to antiretroviral therapy (ART), increasing numbers of children infected perinatally are reaching adolescence
- More than 90% of children living with HIV are infected through mother-to-child transmission during pregnancy, around the time of birth or through breastfeeding. Children – and adolescents – may also be infected with HIV through transfusion with contaminated blood, injections with contaminated needles, and through early sexual debut and abuse (2)
- Many young people who know their HIV status often fail to access the health and social services they urgently need, from fear of stigma or judgement, or concern that their HIV status will be disclosed to others (3)

Sources: 1. UNAIDS Report on the Global AIDS Epidemic. UNAIDS, Geneva, 2010. 2. Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector. WHO/UNAIDS/UNICEF, Geneva, 2009. 3. We can empower young people to protect themselves from HIV. UNAIDS, Geneva, 2010



Students from Chiwoko Basic School, a school piloting sexuality and health as a regular subject on the curriculum, perform a dance and drama display on HIV awareness. Chiwoko Village, Zambia © Nell Freeman for the Alliance

RESEARCH SUMMARY AND BACKGROUND

RESEARCH OBJECTIVES

1. Understanding the sexual and reproductive health (SRH) needs of young people and adolescents living with HIV in Zambia.
2. Gathering information about the nature and extent of current HIV services and support structures available for this group.
3. Exploring issues around access to and utilization of HIV services, and highlighting areas requiring improvement and refinement.

The aims of this qualitative study, carried out in 2010, were twofold. The first was to explore and document the psychosocial, sexual and reproductive health (SRH) needs of adolescents (10-19) living with HIV in Zambia. The second aim was to identify gaps between these needs and existing SRH and HIV-related initiatives and services currently available to young people. Funding for the study was through the International HIV/AIDS Alliance Africa Regional Programme (ARP), with financial support from the Swedish development agency (Sida).

“ I’m scared of having a boyfriend because my mum has told me not to have a boyfriend. She says it is bad for someone in my condition”

14 YEAR OLD GIRL

The need for this study arose out of concerns that the growing number of adolescents and young people living with HIV are not receiving consistent, age-appropriate support from HIV services especially in relation to sexuality, relationships and tailoring lifestyles around their HIV status. In addition, as antiretroviral treatment (ART) is rolled out and access becomes more viable, adolescents living with HIV require increasingly sophisticated interventions to ensure that the benefits of ART are maximised.

DESCRIPTION OF THE PROJECT

Qualitative data were generated through semi-structured interviews and focus groups with: young people living with HIV (116); Key Informants, including medical/nursing staff and counsellors (38); and parents/guardians (13). Three Zambia regions were selected – Lusaka (urban), Kitwe (urban) and Kalomo (rural) – and interviews conducted in health centres and NGO offices.

Adolescents living with HIV were selected on the basis of their age (10–19), and their enrolment in HIV services for treatment and monitoring in the three regions.

Data collection, analysis and report writing and dissemination of results were supervised by an advisory research group, and ethical approval was granted by the local ethics committee at the University of Zambia.

FINDINGS

Following qualitative, inductive analysis of data, the findings provide a number of insights into the experiences of living as a young person with HIV, nature and effectiveness of HIV service providers, and the intersection between the two.

A number of themes emerged in the data, including:

Immediate social networks: For ongoing support, these have significant impact on the ability of young people to adhere to treatment, and come to terms with their HIV diagnosis.

Diagnosis: Being diagnosed with HIV is traumatic, and where parents are also infected there are additional difficulties if disclosure of parents' and the young person's status is poorly managed.

Impact: HIV – either directly or by proxy – affects significantly the agency of young people. Choices are affected, and the need to acquiesce with safe sex and ART adherence creates a more difficult experience of adolescence.

Information: Young people are often seeking information – they are expectant – and HIV service providers in some instances are clearly unable to meet the informational requirements of young people. Tailored and participatory events for information and social needs are appreciated greatly.

Services: HIV support services vary in their capacity to meet the needs of this group. Treatment support is generic, but addressing the social and psychological needs are more fragmented. Respondents in the lower age groups have relatively limited insights into some aspects of SRH, and what support is available. Services that are welcoming, empowering and willing to share specific information about individual needs are highly valued.



A game of tag designed by Sports in Action to educate youth about HIV, Zambia © Gideon Mendel for the Alliance

DISCUSSION AND IMPLICATIONS

The data confirms that for young people, living with HIV amplifies the need for effective support and guidance, and as they move from child to adolescent to adult, there are a range of HIV-related factors impacting on their day to day lives. Respondents identify key interventions they perceive could improve the effectiveness of HIV service providers, and there are three levels to address when considering implications:

On the personal level: Young people living with HIV must be encouraged and motivated to access local support groups and providers of psychosocial support in their community. Evidence suggests meeting with experts and other affected people can help offset some of the problems around adherence, especially if there is lack of people (outside of the family) to discuss some of the more complex aspects of HIV infection.

On the organisational level: Service providers delivering HIV, SRH and psychosocial interventions can play an active role in facilitating earlier testing of children at risk of HIV, and also supporting the process of disclosure – of the child's own status and of the parents'. There is also potential for greater integration between service providers and parents / guardians, promoting integrated and seamless support. Finally, information cohesion (organisation, family, media, and faith-based) can go a long way in ensuring an end-user (the young person) is not presented with conflicting messages.

On the level of policy: Funding youth friendly HIV and SRH services in both urban and rural settings should be a key priority. There must be adequate support for clinic-based health care workers and NGOs as they support young people. In many ways this client group is the most complex, subject to rapid social and physical transition. Ongoing assessments must be in place to ensure services meet the needs of an adolescent at each point in their development.



Peer education in Zambia © Nell Freeman for the Alliance

“ NGOs offer better services than... clinics. Most providers are not child friendly environments”

FOCUS GROUP



A global partnership:
International HIV/AIDS Alliance
Supporting community action on AIDS in developing countries

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ABOUT EVIDENCE FOR ACTION (EFA)

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, examining issues surrounding HIV treatment and care systems.

The research is organised in four key themes:

1. What 'package' of HIV treatment and care services should be provided in different settings?
2. What delivery systems should be used in different contexts?
3. How best should HIV treatment and care be integrated into existing health and social systems?
4. How can new knowledge related to the first three questions be rapidly translated into improved policy and programming?



EFA PARTNERS:

- International HIV/AIDS Alliance, UK
- Lighthouse Trust, Malawi
- London School of Hygiene and Tropical Medicine, UK
- Medical Research Council Uganda Research Unit on AIDS, Uganda
- Medical Research Council Clinical Trials Unit/University College London, UK
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