

HIV and Adolescence: epidemiology and care

Rashida Ferrand - Reader in International Health, London School of Hygiene and Tropical Medicine, UK.

The burden of HIV infection in adolescence

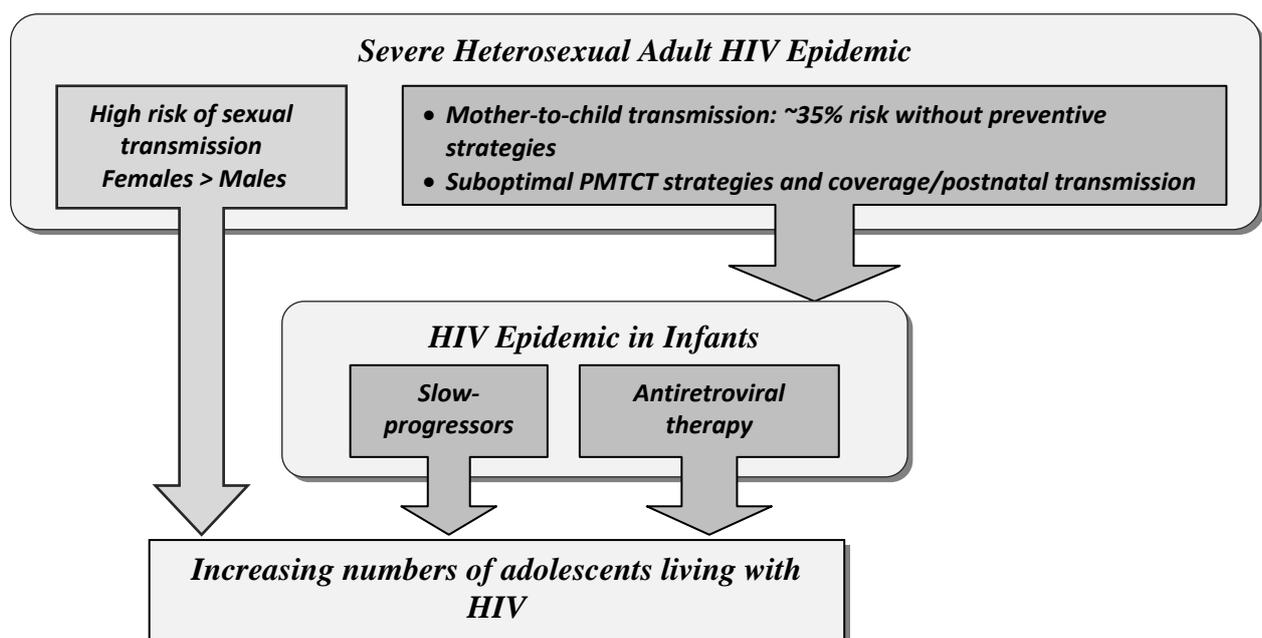
More than three million children worldwide are infected with human immunodeficiency virus (HIV), approximately 90% of whom live in sub-Saharan Africa (1). The burden of the paediatric HIV epidemic is rapidly shifting towards adolescents (Figure 1). Compared to a decade ago when HIV-infected infants faced inevitable death, survival prospects for children have improved dramatically over the past years due to the increased availability of antiretroviral therapy (ART), so that increasing numbers of children living with HIV are now reaching adolescence. This trend is accentuated by the decline in new infant infections as a result of scale-up of interventions to prevent mother-to-child transmission (PMTCT). The large numbers of adolescents in HIV programmes in sub-Saharan Africa are, however, not fully explained by increased ART-related survival. Over the last decade, substantial numbers of children with perinatally-acquired HIV have been presenting to healthcare services for the first time during adolescence, having lived with untreated HIV for a decade or more. Based on extrapolation of the high early mortality associated with untreated HIV in the early days of the HIV epidemic, the widely-held perception was that survival to older childhood without treatment in sub-Saharan Africa would be exceptional. However, epidemiological data are

consistent with at least a third of HIV-infected infants being slow progressors who have a 50% probability of survival up to at least 16 years without treatment (2). The numbers of perinatally-infected adolescents accumulate slowly after the onset of the adult epidemic due to the time needed for infants to reach older childhood. Even with universal access to PMTCT interventions and with scale up of ART there will be a time lag of two decades before the numbers of perinatally HIV-infected adolescents decrease. In addition, adolescents continue to be at high risk of acquiring infections through sexual transmission.

Complexities of addressing HIV infection in adolescence

Overall, the number of HIV-related deaths has fallen sharply as a result of the global scale-up of ART. However, among adolescents the mortality gains have been much more modest compared to those in adults and younger children and this is the only age-group in which HIV-related deaths are still rising. Notably, HIV infection is now the leading cause of mortality among adolescents in sub-Saharan Africa. The structural complexities involved in managing HIV infection in adolescence are substantial. For those not yet diagnosed, age-appropriate HIV testing services are woefully inadequate.

Figure 1: Evolution of the paediatric HIV epidemic in sub-Saharan Africa (3)



The prevalence of undiagnosed HIV infection is substantially higher in adolescents than other age groups, with global estimates indicating that less than 40% are aware of their HIV status in low- and middle-income countries (4). HIV testing and counselling is the critical first step to accessing HIV treatment and prevention services. The World Health Organization (WHO) recommends that every individual attending a health care facility in a high HIV burden setting should be offered HIV testing regardless of the cause of attendance. However, health facility usage rates among adolescents are low globally due to substantial personal, social, legal and structural barriers, thus excluding them from accessing key health services. Coverage of HIV testing among adolescents who do attend health facilities is low: in a study conducted in seven primary care clinics in Harare, Zimbabwe, only 54% of 6-16 year olds underwent HIV testing, the key reason for low coverage being that healthcare providers did not offer HIV testing (5). Health care workers tended to offer testing to adolescents presenting with conditions indicative of HIV, which likely identifies individuals when they have developed advanced disease, and prioritised pregnant women and adults when the supply of HIV testing kits was limited (5). The requirement for consent from a guardian to undergo HIV testing poses an additional challenge, given that many adolescents living with HIV are orphaned and have changing or ill-defined guardianship (5). Community-based HIV testing and counselling (HTC) strategies may be able to diagnose individuals at an earlier stage of infection by being more easily accessible and not relying on health care providers' discretion or on a client visiting a health facility. In recent years, community-based HTC strategies have improved uptake, but the overall coverage among adolescents remains low (e.g. about 20% of 16-17 year olds tested in a large trial of a community-based mobile HIV testing intervention in 48 communities in Africa and Asia) highlighting the need to engage this age-group (6).

Identifying currently undiagnosed adolescents will only result in successful treatment outcomes if combined with an effective strategy to enhance linkage to care. Coverage of ART is much lower in adolescents than in adults and more than a third do not stay in care. In addition, HIV programmes to date have predominantly focused on delivery of ART, with little consideration of the evolving and complex needs of HIV-infected children as they grow, despite the rapidly growing numbers. We are only beginning to learn about the consequences of HIV infection acquired at a critical period of development when the immune system is not fully developed. Over and above the typical infectious manifestations, longstanding HIV infection is

associated with growth failure and damage to organs (including the brain, heart and lung) which, once established, is not always reversible with ART (3). The consequence is a high prevalence of disabilities related to HIV, such as blindness, deafness and learning impairment, which requires multidisciplinary care that is not provided in HIV care programs. Clinical management is complicated by our sparse knowledge of the long-term adverse effects of ART in children.

Maintaining sustained adherence to ART is the crux of successful treatment. Treatment failure results in drug resistance, disease progression and risk of onward HIV transmission once sexual debut occurs. Adherence to treatment of chronic illnesses drops off during adolescence and, unfortunately, HIV is no exception (7). The complexity of the social milieu within which adolescents live with HIV is vastly underappreciated. The stigma that surrounds HIV leads to adolescents children taking their treatment in secret. Desire to conform with peers is an important feature of adolescence and may inadvertently lead them not only to stop treatment, but can also instil in them a pronounced sense of social isolation by being marked out as different, which creates a heavy psychological burden. They are more likely to have suboptimal educational achievements due to school attendance being interrupted by illness and clinic visits and potential learning disadvantage through HIV-related cognitive impairment. They consequently have less chance of being productively employed and gaining economic independence. Adolescents have to negotiate vulnerable health, the complex demands of treatment, social pressures as well as sexual relationships within the context of bereavement and disrupted care. The skills to manage these circumstances can only be developed with an in-depth knowledge and understanding of their illness. However, disclosure to adolescents of their HIV status is commonly delayed and is typically a one-off event, leaving them to cope with their condition within an atmosphere of secrecy and confusion about their future as they approach adulthood (8).

Strategies to improve treatment and cure for HIV positive adolescents

The latest World Health Organization (WHO) guidelines recommend immediate initiation of ART in all individuals living with HIV, irrespective of age or disease stage (9). Thus, a substantially larger number of individuals living with HIV, many of whom remain undiagnosed, will be eligible for treatment. In addition, there is a risk that asymptomatic patients will discontinue treatment as a result of having no perceived short-term benefits from ART. To achieve the ambitious UNAIDS 90-

90-90 targets, which aim to identify 90% of people these on ART, and achieve viral suppression in 90% of these, there is now an even more pressing need to improve HTC and coverage of ART, particularly important among adolescents, a group that is difficult to reach and has disproportionately poor health outcomes. To date, most strategies to achieve this have replicated those developed for adults with little consideration for the specific needs of this age group. Context-specific strategies for earlier identification and support for prompt linkage to and retention into care and adherence for HIV-infected adolescents need to be developed. Management of chronic illness through provision of episodic emergency care is insufficient. Practical disclosure strategies that enable adolescents to learn about what it means to grow up with HIV, their responsibilities and the skills to manage the social consequences of living with HIV need to be integral to delivery of ART. Clinical care should integrate age-appropriate sexual and reproductive health, educational and psychosocial support services. These need to be tailored to account for the heterogeneity in physical, mental and social development across the target age-group. There is also a need to better prepare adolescents for transition to adult services to ensure that they are not lost to follow-up at this critical juncture. Healthcare workers will need to be trained to recognise and manage the diverse needs of this age-group and to support caregivers, who are critical mediators to adolescents achieving optimal health outcomes. Complementary community-based strategies and task sharing may enable care to be provided more sustainably and cost-effectively.

The remarkable expansion in access to ART globally since 2004 has transformed HIV from a life-threatening into a chronic illness. Improved survival as a result of ART has starkly highlighted the lack of preparedness amongst health systems to deal with the complex needs of children living with HIV as they grow older and enter adolescence. While the drive to increase coverage to ART needs to continue, there is also an urgent need for policymakers and healthcare providers to focus beyond the goal of prolonging survival and to concentrate ensuring that adolescents living with HIV achieve an optimum quality of life.

living with HIV through testing, initiate 90% of

Rashida Ferrand - Reader in International Health, London School of Hygiene and Tropical Medicine, United Kingdom. Research interests: Rashida has worked with HIV-infected adolescents in Southern Africa for more than a decade. Her research focuses on interventions to improve outcomes at each step of the HIV care continuum and investigation of chronic HIV-related complications in adolescents. rashida.ferrand@lshtm.ac.uk

References:

1. UNAIDS. 2014 Progress Report on the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive. Geneva, Switzerland: UNAIDS; 2014.
2. Ferrand RA, Corbett EL, Wood R, et al. AIDS among older children and adolescents in Southern Africa: projecting the time course and magnitude of the epidemic. *Aids*. 2009; 23(15): 2039-46.
3. Lowenthal ED, Bakeera-Kitaka S, Marukutira T, Chapman J, Goldrath K, Ferrand RA. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *Lancet Infect Dis*. 2014; 14(7): 627-39.
4. Staveteig S, Wang S, Head SK, Bradley SEK, Nybro E. Demographic Patterns of HIV Testing Uptake in Sub-Saharan Africa. DHS Comparative Reports No. 30. Calverton, Maryland, USA: ICF International; 2013.
5. Kranzer K, Meghji J, Bandason T, et al. Barriers to provider-initiated testing and counselling for children in a high HIV prevalence setting: a mixed methods study. *PLoS Med*. 2014; 11(5): e1001649.
6. Sweat M, Morin S, Celentano D, et al. Community-based intervention to increase HIV testing and case detection in people aged 16-32 years in Tanzania, Zimbabwe, and Thailand (NIMH Project Accept, HPTN 043): a randomised study. *Lancet Infect Dis*. 2011; 11(7): 525-32.
7. Nachega JB, Hislop M, Nguyen H, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *J Acquir Immune Defic Syndr*. 2009; 51(1): 65-71.
8. Bernays S, Jarrett P, Kranzer K, Ferrand RA. Children growing up with HIV infection: the responsibility of success. *Lancet*. 2014; 383(9925): 1355-7.
9. WHO. Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. Geneva, Switzerland: WHO; 2015.