Transitioning HIV-positive Adolescents into Adult Care

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Policy Brief

Paediatric AIDS Treatment for Arica (PATA) is an organization dedicated to expanding and improving care and treatment for HIV-positive children and adolescents in Africa. Its primary mandate is to support health and social service providers in delivering quality HIV-care to young people. This demands an enabling policy environment, adequate training and resources and amplifying the voices of frontline clinic workers.

Appropriately managing transition to adult care has emerged as a key challenge for PATA clinics across Sub-Saharan and East Africa. This policy brief draws attention to the difficulties of healthcare transition as they are understood and experienced by frontline clinic providers and offers their recommendations for change.

Transition is defined as…

"A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems"

It is distinct from **'transfer',** which refers to the **event** of an adolescent moving from paediatric to adult services.

When adolescent TRANSFER is not supported by a process of TRANSITION, it is frequently associated with increased morbidity and mortality, as well as low adherence and retention in care.

[Transition] is a very important process that I feel many facilities are lacking (Sybil Modise, healthworker and PATA member)

Background

There are 1.2 million adolescents living with HIV in Sub-Saharan Africa (UNICEF, 2012). Mass rollout of antiretroviral treatment means that most of these young people will transition into adulthood. With improved survival, the need eventually arises to transition these young people into adult care services.

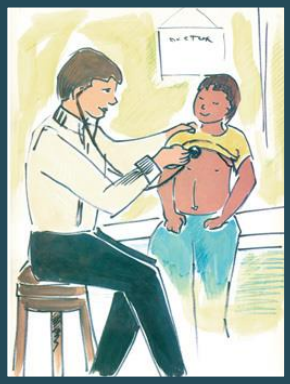
Challenges in relation to such transition include adolescents and their families feeling abandoned by paediatric teams, a lack of skills and capacity in adult-oriented settings to manage adolescent needs, and difficulties in facilitating adolescent self-care. An unsupported transition can be detrimental to adolescent treatment adherence, retention in care and long-term chronic illness management.

Adolescence is a period of significant physical, psychological and social changes. For HIV-positive youth, the pressures of adolescence may be compounded by fear of stigmatization, psychosocial and behavioural problems or mental illness. It is important that healthcare programmes and policies recognise and adapt to the specific clinical and psychosocial needs of these adolescents.

49 PATA clinics identified common differences between paediatric and adult care services, which serve as barriers too successful transition…

Paediatric Care

- Adolescents attend clinic alongside their caregivers.
- Adolescents establish trusting relationships with service providers.
- Care is personalized and adolescent-specific.
- Healthworkers have smaller case loads.



Adult Care

"*Most adolescents feel they can't assert themselves at an adult clinic*" (Baylor Clinic, Lesotho)

- Higher patient numbers and levels of congestion.
- Less personalised care.
- Lack of confidentiality.
- Care is not tailored to adolescent needs.
- Adult services often charge a high service fee.
- Adolescents are expected to be fully disclosed, responsible for their own medication-taking, and treatment literate.
- Adolescents are frequently stigmatized as sexually deviant and irresponsible.

Challenges to Transition

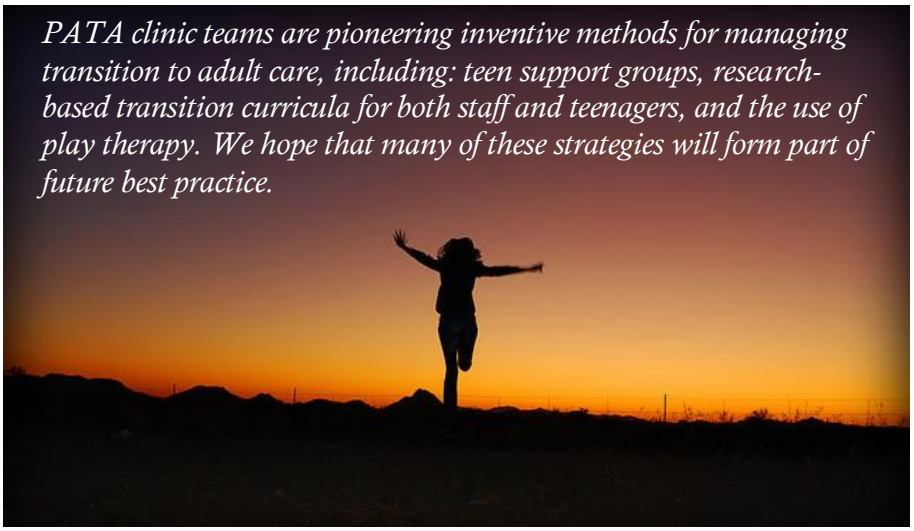
49 PATA clinic teams identified the following challenges to successful healthcare transition:

- Clinic staff at both paediatric and adult units are not trained to manage transition appropriately.
- There is often no health provider assigned to overseeing adolescent transition.
- Transition is poorly supervised and coordinated.
- The procedures for transitioning are not clear or systematized.
- Adolescent do not feel comfortable discussing their health issues in an adult setting.
- There is a lack of good policy and process.
- Adolescent-specific needs are not attended to in adult clinics.
- Adolescents and their families experience separation anxiety leaving the paediatric clinic staff.
- Adolescent capacity for self-care and independence is questioned, and at times restricted, by adult caregivers.
- Adult clinics are reluctant to take on the additional adolescent caseload.

"*Personnel in the adult unit were not prepared for the transitioning process and the personnel in the paediatric unit were also not prepared…the process of transitioning was not clear*" (PATA clinic, South Africa)

Recommendations from PATA clinic teams

- Transition should be a collaborative process that includes caregivers, adolescents, as well as paediatric and adult services providers.
- Transitions should begin early and include facilitated, supported disclosure to adolescents about their own HIV-status.
- Healthworkers should be trained to facilitate adolescent transition.
- There should be a continuity of care between paediatric and adult services.
- Adult units should offer youth-friendly services and preferably adolescent-specific hours that do not clash with school hours.
- Counselors and social workers should be involved in addressing the psychosocial issues of transition.
- There should be clear procedures and guidelines for transition and detailed case notes for adolescents.
- There needs to be post-transition follow-up.
- Clinics need the resources to manage transition, including designated staff, age-specific materials, enabling policy and sufficient clinic space.
    - Transition needs to be a process not a once-off event



Conclusions

Current models for adolescent healthcare transition have been developed in resource-rich settings. There is a paucity of evidence on how to support adolescents moving to adult care in the developing world. The practices and experiences of frontline clinic teams in Africa provide an invaluable starting-point for policy and programming in this area.

Drawing on the experiences of clinic-based healthcare teams, PATA will be working to build a strong evidence base documenting transition practices and outcomes. Our hope is that this will inform more relevant tools and guidelines for facilitating healthcare transition in Africa. If we fail to ensure successful healthcare transition for adolescents, the gains of paediatric ART programmes over the last decade will be quickly be undone, as young people are lost in the crowd. This serves as an urgent call to policymakers, funders and programmers to provide clinic teams the support, training and resourcing that successful transition demands.

For more information, contact:
Daniella Mark
daniella@teampata.org
Fiona Mpungu
Fiona@teampata.org

Useful Resources

Foster, C. (2010) 'CHIVA Guidance on Transition for adolescents living with HIV'

USAID/PEPFAR (2012) 'Transitioning of care and other services for adolescents living with HIV in Sub-Saharan Africa: Technical Brief'

Katusiime, C.; Parkes-Ratanshi, R.; Kambungu, A. (2013) 'Transitioning behaviourally infected HIV-positive young people into adult care: experiences from the young person's point of view', Southern African Journal of HIV Medicine, 14(1)

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,* 23(15): 2039-46 (2009).

Bekker, LG. (2013) 'Teen to Grow Up: Falling through the Cracks, Lost in the Crowd or Thriving Adult'. International AIDS Society conference, Kuala Lumpur

New York State Department (2013) 'Transitioning HIV-infected adolescents into adult care'.