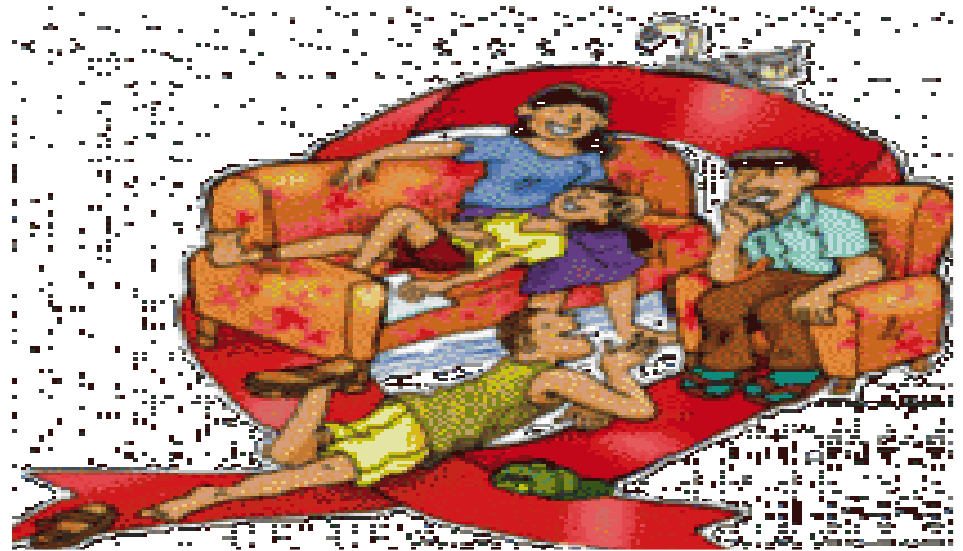


Adolescents with HIV

Specific Issues and a Model of Care

By Dr Cathy D. Kalombo



DEFINITION

Adolescence begins with biological maturation (puberty), when young people must accomplish developmental tasks and develop a sense of personal identity. It ends when young people achieve self-sufficient adulthood as defined by society.



"Don't call me a teenager. From now on, I want to be referred to as a pre-adult."

Adolescence

A period marked by complex changes, such as:

- Rapid physical growth
- Rise of reproductive sexuality
- New social roles
- Growth in thinking, feeling and morals
- School transitions



WHO classifications

- Young people: 10 – 24 years
- Adolescence: 10 – 19 years
- Youth: 15 – 24 years

Also defined within the cultural context of individual countries. The SA national youth policy 2009-2014 defines youth as any person between the ages of 14 to 35.

Developmental stages

- Not a homogenous group
- Different ages, developmental stages differ :
 - Early Adolescence: 10 – 13 years
 - Middle Adolescence: 14 – 17 years
 - Late Adolescence: 18 and older
- Therefore, different needs at different stages

HIV disease burden

- Young people are at the center of the HIV epidemic.
- 15 – 24 year olds are the most impacted.
- 42% of all new adult HIV infections worldwide in 2010 (*UNICEF, update, 2012*).
- Highest burden is within developing countries.
- Sub-Saharan Africa is home to 63% (i.e. 6.2 million) of 15 – 24 year olds living with HIV.
- Aids-related mortality among adolescents has increased by 50% over the past seven years, but fell for all other age groups, according to UNAIDS estimate.

- There is an urgent need that ALHIV become aware of their status and have access to effective HIV treatment and quality care programs.
- Two categories of HIV+ adolescents and young people:
 - Perinatally infected
 - Behaviorally acquired HIV

ART and adolescents

- Prior to ART, approximately 50% of perinatally infected children were expected to die before the age of 2 years.
- The survival of perinatally infected HIV+ children to adolescence is increasing in Sub-Saharan Africa as the epidemic matures due to ART.
- Now the survival rate is similar to that of adults (*Ngalzi et al, 2012*).

Outcomes in perinatally infected adolescents vs. all adolescents

| Rates (per 100 PYS) | All adolescents | Perinatally infected adolescents |
|------------------------|-----------------|-------------------------------------|
| Mortality | 1.2 (0.3-4.8) | 0.8 (0.1-5.5) |
| LTFU | 7.2 (4.1-12.6) | 3.9 (1.6-9.4) |

Ngalzi et al, 2012.

Major challenges

1. Living with HIV
2. Stigma
3. Disclosure vs. non-disclosure
4. Adherence
5. Reproductive health and sexuality
6. Mental health
7. Transition to adulthood?

Living with HIV

Recent data collect from Sub-Saharan Africa indicate that only 10% of young men and 15% of young women (14-24years) are aware of their HIV status. (UNAIDS features..2014)

A study by Li and colleagues found:

- ALHIV viewed HIV as physically and emotionally painful.
- A Strong family and friend support systems regarded as positive aspects of their lives.

(*Li et al,2010*)

Stigma

- Social and economic environments shape attitudes and perspectives of ALHIV.
- Stigma remains an issue. The situation is even more difficult for the youth in the key population, who face discrimination on account of the behavior that makes them vulnerable to HIV. (MSM)
- Most ALHIV experienced rejection and gossip. (Strydom and Raath, 2005)
- Clinic environment: comfortable, accessible, non-judgmental (needed)

Disclosure

- The most complex and emotive subject amongst those affected and infected. The total lack of support to disclose their status leads to anxiety and depression.
- The dilemmas:
 - when to disclose
 - how to disclose
 - to whom do you disclose
 - What is the psychological impact of the news

Disclosure is a process rather than a once off event.

Disclosure

- Care-giver reluctance to disclose:
 - Child readiness
 - Child's ability to maintain confidentiality
 - Protect the child from stigma
 - Parental guilt
 - Anxiety regarding the child's emotional reaction

Non-disclosure

- Through advertising and education many children figure out their diagnosis on their own.
- If this happens before disclosure occurs they internalize the stigma, which has a negative effect on their self-esteem and identity formation: usually leading to anger.

(NWoollett, 2013)



Adherence

- It is a challenge among ALHIV as they grow older.
- Needs to be >95% consistently and is critical to their emotional, physical and psychological well-being.
- Poor adherence is associated with neurocognitive deficit, psycho-social and behavioral problems e.g. substance abuse, sexual risk activity.

(deficit involving speech, memory, information process..)

(Kapetanovic et al 2011, Chanwani et al, 2012)

Barriers to adherence

- Forgetfulness
- Changes in daily routine
- Escalating social agendas
- High pill burden and pill fatigue
- Drug side-effects
- Disclosure
- Lack of community support system, counseling
- Absence of information about their sexual and reproductive health rights.

- * Adolescents have expressed their frustration towards the absence of information about their sexual and reproductive health and rights, as well as the need for information and skills around safe sex practices.
- * Comprehensive sexuality education that is catered to the unique need of ALHIV is missing from most schools and healthcare settings globally.



Facilitating Adherence

- Improve adherence organizational skills
- Disclosure
- Empowerment through knowledge
- Caregivers' workshops, peer support and peer counseling
- Identifying 'pill buddies' in the same community
- Life skills camps (YDP)
- Providing a youth-friendly service

Mental health issues

- All adolescents are emotionally distressed to varying degrees.
- Complicated by HIV infection.
- Feelings of depression, social withdrawal, loneliness and anger are common among youth struggling to cope with HIV. (*Kamau et al, 2012; Pao et al, 2000; Mellins et al, 2006; Musisi and Kinyanda, 2009*)
- HIV has significant mental health implications. The main neurological condition being HIV–associated progressive encephalopathy. This causes neuropsychological deficits involving a wide variety of domains :speech, language, information processing and motor functioning.

Gugulethu ARV (Hannan Crusaid)

- Launched April 2006 by Linda-Gail Bekker (Desmond Tutu HIV Foundation who is the NGO partner supporting the clinic.)
- Count 220 adolescents from age 10 to 25 years - all prenatally infected.
- Full disclosure is a prerequisite prior to recruitment at the clinic. This happens from the age of 9 years. At 10 years of age the child should know his status and then join the program.

Gugulethu ARV(Hannan Crusaid c)

- Separate waiting area from the adults where different activities are run according to the age group.
- Counselors collect their medication from the pharmacy.
- Additional services e.g. family planning.
- Youth Development Program (YDP) to help with transitioning to adult care.
- Next step: ?ALHIV chronic clubs?

Clinic set-up

- Age stratification, as follows:
 - *10 – 11 years
 - *12 – 13 years
 - *14 – 17 years
 - *17+ years
- “Chill-room”
- Staff multidisciplinary team activities
- Lunch and health education at every visit

CONCLUSION

Treating adolescents can be challenging. They are a vulnerable group who find it difficult to access necessary health services. But this can be overcome with a well trained multidisciplinary team that does not focus only on their treatment and clinical need but also acknowledge their emotional, physical and sexual too.

“The watershed moment in the AIDS response:..critical mass of organizations working to advance Adolescent care agenda”

(Linda-Gail Bekker ,Professor of medicine

Deputy Director of Desmond Tutu HIV F.

THANK YOU

