Adolescents with HIV

Specific issues and a Model of Care

By Dr Cathy D. Kalombo
Age 10-19: WHO

- Period marked by biological maturation (puberty)
- Person accomplish developmental tasks and
- Develop a sense of personal identity with new psychosocial roles.
- Till young person can achieve Society’s self-sufficient definition of adulthood.
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 definitions

- Adolescence: 10 - 19 years
- Young people: 10 – 24 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.
Early Adolescence: 10 - 13 years: preoccupation with self image, same sex peer pressure and high level of mood swing.

Middle Adolescence: 14 - 16 yr: asserting independence is priority, sexual experimentation, lingering concerns over attractiveness.

Breach of boundaries... please remember to draw the line.
Late adolescence 17-20 years:

* Major concerns about career, lifestyle and relationships

* Degree of independence established

* Realistic body image and sexual identification established
ANATOMY OF A TEENAGER'S BRAIN

THE BIRDS AND THE BEES LOBE

REBELLION CENTER

SUPER TURBO REBELLION CENTER

CENTER OF UNIVERSE CENTER

SELF IMAGE

FITTING IN GLAND

INTERNET PHONE ADDICTIONS

PEER PRESSURE RESISTANCE

SLAM DOOR REFLEX

CAR KEYS CRAVING

ABILITY TO BE SEEN IN PUBLIC WITH PARENTS

MEMORY FOR MUSIC

LOVE FOR PARENTS

DINNER FOR PARENTS

SLANG DECODER

JUDGEMENT GLAND

MEMORY FOR CHORES, HOMEWORK, ETC.

“COOL” GAUGE

FLUCTUATOR

PERSONALITY

EXCITEMENT

EVERY EPISODE OF THE SIMPSONS

INDESTRUCTIBILITY CORTEX

PRONE TO BRUISING
* Young people are at the center of the HIV epidemic (15-24 yrs count for key population to target in strategy to eradicate HIV).

* 2 M of ALHIV worldwide with almost 1.7 M living in Sub-Saharan Africa (>83%. Unicef update July 2015)

* 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.
HIV prevalence in South Africa by gender and age, 2012

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

<table>
<thead>
<tr>
<th>Rates (per 100 PYS)</th>
<th>All adolescents</th>
<th>Perinatally infected adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality</td>
<td>1.2 (0.3-4.8)</td>
<td>0.8 (0.1-5.5)</td>
</tr>
<tr>
<td>LTFU</td>
<td>7.2 (4.1-12.6)</td>
<td>3.9 (1.6-9.4)</td>
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<table>
<thead>
<tr>
<th>Perinatally infected youth infected</th>
<th>Sexually infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>F=M</td>
<td>F&gt;M</td>
</tr>
<tr>
<td>Younger</td>
<td>Older</td>
</tr>
<tr>
<td>Under-developed</td>
<td>precocious</td>
</tr>
<tr>
<td>treatment experienced</td>
<td>treatment Naive</td>
</tr>
<tr>
<td>Not disclosed to</td>
<td>Aware of status</td>
</tr>
<tr>
<td>Transitioning paed care adult care</td>
<td>Transition to adult care</td>
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Major challenges of ALHIV

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?
8. PrEP???
Recent data collect from Sub-Saharan Africa indicate that only 10% of young men and 15% of young women (14-24 years) 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 is regarded as positive aspects of their lives.

( Li et al,2010)
Social and economic environments shape attitudes and perspectives of ALHIV.

More difficult for the youth in the key population: subject to discrimination on account of the behavior that makes them vulnerable to HIV. (MSM,Tr.S,Tr.G,.....

Most ALHIV experienced rejection and gossip. (Strydom and Raath, 2005)

Clinic environment: comfortable, accessible, non-judgmental (needed)

‘..i know I am different.i am not like the others.i must take medications all the time...I am sick...I am not free..some time I want to comit suicide’

18yr
* 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.


* Care giver is reluctant to disclosure: readiness? Ability to maintain confidence? Protection from stigma, guilty and anxiety feeling

Disclosure is a process rather than a once off event.
“I used to confront her [mother] about why I am taking treatment. She then told me that I was HIV+. I asked how I got infected. She told me that I was infected by her, I got it from her.....I asked her how she got infected herself, but she did not give me the answers I was looking for. She just kept telling me that I shouldn’t worry; I wasn’t going to die. That I should take my treatment.....I was expecting her to tell that she got it from her mother or she had sex without a condom”

(13yoF).
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.

(N Woollett, 2013)
*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 (lack of support, substance abuse, sexual risk activity,...some times just pill fatigue.

(Kapetanovic et al 2011, Chanwani et al, 2012)
* Barriers to adherence

* Disclosure
* Changes in daily routine (forgetfulness)
* Escalating social agendas
* High pill burden and pill fatigue
* Drug side-effects
  . Lack of community support system, counseling
* Absence of information about their sexual and reproductive health rights. Lack of education on skills on safer sex practices...
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
“You see, when the schools are open, I take them correctly, but when they are closed, I tend to forget. Maybe I oversleep so I miss taking pills. That’s how I get to miss pills”

(14yo M).

“’She went on holiday to her cousin. I didn’t want her to bring her pills. They will not understand and will judge her and make her not welcome”

Care giver
*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)

*The main neurological condition is HIV-associated progressive encephalopathy causing neuropsychological deficits which involves a wide variety of domains: speech, language, information processing and motor functioning.
* No systematic transition process are available in SA.
* Struggle from healthcare provider to let go the relationship with pts since their considered them vulnerable (over protective)
* Fear from healthcare provider of transferring unprepared adolescent to a judgemental, depersonalised, overburdened environment.
* Reciprocal fear of stigmatisation and disclosure of adolescent patients to adults clinic.

Kung, TH & AL. ”SA health care providers perspective on transitioning adolescents into adult care”. SAMJ August 2016
Adolescents perceived adult care as scary and unfriendly
* Difficulty letting go the relationship with the adolescent provider
* Neurocognitive delay associated with perinataly infection interferes with transition process
* Mental problems: depression and anxiety makes difficult the decision of transition.
* Crime and drug abuse in the community may interfere with transition
* Provide support group meeting for adolescents in transition
* Team meeting between adolescent and adults providers to do hand over of patients history
* Introduce the adults care providers to the adolescents while they are still transitioning.
* Develop written guidelines and protocols to post on the wall of the clinic for Drs and Pts to see.
* Follow up appointments with paed Dr after transitioning to adult care
* Provide sexual health counselling at all appointments.
Count 450 adolescents aged 10 to 24 years - predominantly perinatally infected who have transitioned to adolescent and some to adult care. The last group count some behaviorally infected adolescents who have join the cohort.

Disclosure is a prerequisite prior admission at the clinic. From 9yrs the care giver is encourage to prepare the disclosure. At 10years of age the child should know his status and then join the program.

Create an environment of trust, non judgmental where they feel at home and come even when not seeking health.
• Separate waiting area from the adults where different activities are run according to the age group. (they don’t want to mix with adults)

• Don’t queue at pharmacy. Meds are pre-packed same day and counselor collect and hand them at their “chill room” (pre-arrangement with pharmacy), age appropriate activities.

• One stop shop. Full package: TB, STI management, FP, VCT mid/late adolescents

• Well trained staff to address adolescents need (clinicians-counselor-psychologist-social worker=team approach)
YDP with preparation at transitioning into adult care (just publish the founding of this study. Health, life skills education. Support group,

* Adolescent clubs. 18-24. Mixed group of adolescents who have completed the YDP. Same eligibility criteria but differently referred BTC. Functions well

* Negotiating middle adolescent clubs.....with pharmacy
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 health.

‘don’t judge me, instead speak my langage….let me guide you and you will understand how to help me.’

(17yr girl)
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