HIV and adolescents: How do we help them prepare for adult life

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Outlines

- Situation of adolescents living with HIV
- Challenging issues for adolescents living with HIV
- Preparing adolescents living with HIV for adult life
- Conclusions and way forward
Situation of Adolescents Living with HIV, Global 2015

1.2 billion adolescents aged 10-19 years, globally

1.76 million adolescents living with HIV, 80% in sub-Saharan Africa

1.9 million new adult HIV infection, 34% were 15-24 years

UNAIDS 2016 Estimates, Slogrove AL et al. JIAS 2017

UNAIDS 2016
HIV-related deaths among adolescents (10-19 yrs) during 2000-2015

Between 2005 and 2015, the global number of HIV-related deaths fell by 45% (UNAIDS 2016)

HIV-related mortality is declining for younger vertically infected adolescents. Mortality is continuing to increase in older adolescents in the majority of high-burden countries

Slogrove AL et al. CIPHER estimates presented at IAS 2016, Slogrove AL JIAS 2017
Children living with HIV entering adolescence and adulthood

HIV-infected adolescents largely belong to two distinct groups

- Perinatally HIV infected adolescents
- Behaviorally acquired HIV-infected adolescents

UNAIDS 2016
Children with HIV are Living Longer

Estimated Number and Age of 11,761 Persons Living with Perinatally Acquired HIV Infection

- 62% (1 year)
- 17% (3 years)
- 21% (5 years)
- 1% (≥10 years)

38,356 youth (13-24) living with HIV including 7,296 perinatally acquired HIV+ youth

The US CDC HIV Surveillance Report 2014 (50 states)

Number of Children and Adolescents Living with HIV/AIDS, Thailand 2008-2014

Source: NAP Plus 2008-2014, NHSO
<table>
<thead>
<tr>
<th>Perinatally infected</th>
<th>Behaviorally infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>More likely to be in advanced stages of HIV</td>
<td>Earlier stages of HIV</td>
</tr>
<tr>
<td>More likely to have opportunistic infections</td>
<td>Fewer opportunistic infections</td>
</tr>
<tr>
<td>More likely to not be on first-line drugs and in need of complex ART regimens</td>
<td>Less likely to need ART and resistance to ART less likely</td>
</tr>
<tr>
<td>More obstacles to achieving self-management and autonomy</td>
<td>Less likely to experience obstacles to achieving self-management and autonomy</td>
</tr>
<tr>
<td>More physical and developmental delays</td>
<td>Less likely to have physical and developmental delays</td>
</tr>
<tr>
<td>Higher risks of complications during pregnancy</td>
<td>Lower number of complications during pregnancy</td>
</tr>
<tr>
<td>Higher mortality rates</td>
<td>Long-term chronic disease outlook</td>
</tr>
<tr>
<td>May not know HIV status although may have been in treatment</td>
<td>May experience more adherence challenges</td>
</tr>
<tr>
<td>More likely to have experienced multiples losses related to HIV (parents, siblings, etc.)</td>
<td>More likely to have denial and fear of HIV</td>
</tr>
<tr>
<td>More secrecy regarding disclosure</td>
<td>More likely to be misinformed about HIV</td>
</tr>
<tr>
<td>Struggling with issues related to engaging in intimacy, sexuality, and sexual identity</td>
<td>May distrust clinical facilities</td>
</tr>
<tr>
<td>May have heightened concerns about pregnancy and starting families</td>
<td>Lack of belief in clinical treatment to prevent vertical HIV transmission</td>
</tr>
<tr>
<td>More likely to have support from family/caregiver and health provider</td>
<td>More likely to lack familial, clinical, and social supports</td>
</tr>
</tbody>
</table>

Challenging Issues For The Grown-Up Adolescent with HIV
Challenging Issue#1: Consequences of long-term Treatment in Adolescents Living with Perinatally Acquired HIV Infection

- Dyslipidemia in 20-30%
- Insulin resistance in 15%
- Cardiomyopathy detected by echocardiography in 10%

Increase Carotid intima-media thickness compared with control uninfected children

Low Bone Mineral Density compared with control uninfected children by gender

Increase risk of renal lab abnormalities, chronic renal complications

Charakida M et al. Circulation 2005;112:103-9

Sztam et al. J ped gastroent Nut 2011


Comparative risk of hypertension, diabetes mellitus, renal failure, cardiovascular disease, and fracture, by age, among patients versus control subjects.

Challenging issue #2: Cognitive Development and Mental Health

Neurocognitive domains affected in perinatally HIV-infected children

- Intelligence scores:
- Processing speed:
- Verbal Fluency:
- Memory:
- Visual spatial memory/integration:

Significantly lower compared to age-appropriate norms

Laughton B et al. Journal of the International AIDS Society 2013, 16:18603
Mental Health in HIV-Infected Children and Youth

- Review of 8 studies including 328 HIV-infected children age 4-21 years; data were compared to prevalence in overall population.
- Prevalence of mental health disorders:
  - Attention deficit disorder: 24%
    - 6.0-fold increased risk ratio
  - Anxiety disorder: 29%
    - 3.8-fold increased risk ratio
  - Depression: 25%
    - 7.1-fold increased risk ratio

Scharko AM. AIDS Care 2006;18:441-5
Mental Health in Youth (16-24) Living with HIV, ATN network (N=2030, 20 adolescent HIV clinics), USA

Prevalence of clinical psychological symptoms was significantly greater in youth with behaviorally acquired HIV compared to those perinatally acquired infection.

Overall, 17.5% of youth reported psychological symptoms greater than the normative threshold on the Global Severity Index.
Adherence rates tended to decline with age, with worst adherence rates among youth 15-18 years.

Factors associated with poor adherence in adolescents:
- Simply forgetting
- Fears of disclosure
- Inconsistent daily routine
- Adverse effects of the medication
- Not understanding the need to take medication when one feels well


Can we achieve 90-90-90 among adolescents living with HIV?

HIV Treatment and care cascade
The estimated adolescent (13-29 year-old), USA

Adolescents living with HIV had lower rate of retention to care and VL suppression compared to adult living with HIV


Thai NAP web report 2016

The cascade could be worse in less resource-settings
## Summary of adolescent-specific 2016 WHO recommendations

### 1. When to start ART

- **Initiated ART in all APLHV regardless of WHO clinical stage and CD4 count.**  
  *Conditional recommendation, low-quality evidence*

- **Priority for severe or advanced HIV clinical disease (WHO stage 3 or 4) and CD4 count ≤ 350 cells/mm³.**  
  *Strong recommendation, moderate-quality evidence*

### 2. First-line ART

- **Preferred option:** TDF + 3TC (or FTC) + EFV (FDC)  
  *Strong recommendation, low-quality evidence*

- **Alternative options:** TDF + 3TC (or FTC) + DTG or TDF + 3TC (or FTC) + EFV<sub>400</sub>  
  *Conditional recommendation, low quality evidence*

### 3. Youth-friendly health services:

- **Youth-friendly health services** should be implemented in HIV services to ensure engagement and improved outcomes  
  *Strong recommendation, low-quality evidence*
Challenging issue #4: Stigma and Disclosure

Lifetime perceived and enacted HIV stigma among Young PLHIV (16-29 yrs) with substance abuse, USA 2006, (N=147)

- Overall stigma
- Shame Dimension: Felt blamed by others, felt ashamed, thought HIV was punishment
- Social Rejection Dimension: Feared family rejection, feared losing friends
  - Lost friends, heard HIV AIDS joke, shut out by a family member
- Abuse Dimension: Beaten up, verbally threatened
- Avoidance Dimension: Felt others were uncomfortable, felt people avoided you
  - Someone refused to eat with, refused to hug, had children kept away from you

Median age 23 yrs. 79% male (gay/bisexual 74%). 39.5% HIV symptomatic and 26.5% AIDS

Swendeman D et al, Health Psychol 2006
Sexual Risk Behavior Among Youth With Perinatal HIV Infection in the United States

Figure 1. Percentage of youth perinatally infected with human immunodeficiency virus who have had sexual intercourse, by age (n = 330).

62% reported unprotected sex
Cumulative Incidence of First Pregnancy in 174 Perinatally HIV-Infected Sexually Active Girls Age >13 Years, PACTG 219C

By age 19 years, 24% of sexually active girls had been pregnant at least once (6 had 2nd pregnancy, 1 had 3rd)

Invasive cervical cancer risk among HIV-infected women: A North American multi-cohort collaboration prospective study

N=13,690 HIV+(66,249 py)
12,021 HIV-(70,812 py)

Need Vaccination in HIV-infected adolescents

Abraham AG. JAIDS 2012 Dec 18.

Risk of Invasive cervical cancer (times higher of HIV)

- >350: x 2.3
- 200-350: x 3
- <200: x 7.7
Challenging issue 6: Transition

Adolescence/young adulthood

- Identity
- Autonomy
- Mastering abstract thought
- Education, career
- Intimate relationships, families

Early (12-14 yrs)      Middle (14-17 yrs)      Late (17-21 yrs)
Estimated minimum mortality rates by age and type of HIV care in perinatally HIV-infected young people (PHIV+), 2006–2011, UK (N=996)

<table>
<thead>
<tr>
<th>Age group and type of care</th>
<th>Rate/100 person-years (95% CI)</th>
<th>Rate ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-15 years, pediatric</td>
<td>0.2 (0.1–0.6)</td>
<td>1.0</td>
</tr>
<tr>
<td>16-20 years, pediatric</td>
<td>0.3 (0.1–1.0)</td>
<td>1.4 (0.2–8.6)</td>
</tr>
<tr>
<td>16-20 years, adult</td>
<td>0.5 (0.2–1.3)</td>
<td>2.7 (0.6–12.2)</td>
</tr>
<tr>
<td>&gt;21 years, adult</td>
<td>0.9 (0.3–2.3)</td>
<td>4.9 (1.1–22.0)</td>
</tr>
</tbody>
</table>

Fish R et al. HIV Med 2014

Poor consequences for PHIV+ following their transfer to adult care

Kakkar et al. BMC Pediatrics 2016
Behavioral-acquired HIV attempted transfer at an older age compared to perinatally-acquired HIV, the groups did not differ in rates of linkage and retention in adult care.

Ryscavage P et al. AIDS Care 2016
Goals of Preparing Adolescents living with HIV for Adulthood

- Preserve normal life: life-style, education, career, sex, family, self-esteem
- Prevent long-term complications
- Promote retention in care and VL suppression
- Prevent HIV transmission
- Encourage to take increasing responsibility for their health, work and life decisions
Definition of Transition

“The planned, purposeful 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-centered to adult oriented health care system”

NYS DOH AIDS Institute. Transitioning HIV-infected adolescents into adult care 2011
Department of Health, UK Transition: getting it right for young people 2006
Adolescents living with HIV
- Not accessing/attending services
- Not aware of diagnosis
- Lack of HIV knowledge/skills
- Psychosocial problems
- Self-stigma
- Resists of transition

Family/caregiver
- Not promoting adolescent autonomy
- Not engaged in the care of youth
- Not able to provide full support to youth
- Resists the transition

Health policies
Lack of formal policies/guidelines

Providers
- Pediatric difficult to let go
- Weak understanding of what is needed for transition
- Adult providers don’t understand adolescents’ holistic needs
- Lack of communication between ped-adult providers/provider-patients
- Resists

Health services
- Not youth friendly
- Medicalization of clinics
- Information is poorly given
- Abrupt transfer, no prior preparation
- Differences between ped/family care and adult/individual care

System
- Logistic, transportation
- Economic
- Health insurance
- Lack of system to track youth after transition

Guidance on Readiness Preparation and Transition Youth Living with HIV to Adult HIV Care Services

Draft May 11, 2012
Last updated Sep 9, 2014

Bureau of AIDS, TB, STIs, Thailand Ministry of Public Health
Thailand MOPH-U.S. CDC Collaboration

With advances in antiretroviral therapy, most HIV-infected children survive into adulthood. Optimal health care for these youth includes a formal plan for the transition of care from primary and/or subspecialty pediatric/adolescent/family medicine health care providers (medical home) to adult health care providers. Successful transition involves the active involvement and participation of the youth and his or her family in the planning and decision-making process.

KEY WORDS: Pediatrics, HIV, health care transition, adolescent, adult, ambulatory care

ABREVIATIONS:
AAP—American Academy of Pediatrics
ART—antiretroviral treatment
EMR—electronic medical record
HIVMIS—malaria who have sex with men
Transition Programming: What Exists: Some examples

‘Movin’ Out’ 5-phase transition model, Special Adolescent Clinic, Miami, USA

6-phase model, Infectious Disease Clinic, Makarere University, Kampala, Uganda

Generic 4-phase model for transition adapted from ‘Movin’ Out’, USAID

Other transition programs reported from Brazil, Sweden, Thailand, UK, USA, Australia, Jamaica, Ukraine, Cambodia, etc.

Common Recommended Elements for Successful Transition
1. Having written policy for transition process

- Define the process of transition
- Share the plan with all pediatric/adolescent or family medicine providers, staff, and patients and their families
- Provide appropriate staff training
- Establish a system to identify and track youth as they progress through the transition process

**NYS DOH: Transitioning HIV-infected adolescents into adult care**

**AAP. Pediatrics 2013**
When to Transition

<table>
<thead>
<tr>
<th>Region</th>
<th>Age at transition</th>
</tr>
</thead>
<tbody>
<tr>
<td>America, Europe</td>
<td>18-25 yrs</td>
</tr>
<tr>
<td>Africa</td>
<td>10-19 yrs</td>
</tr>
<tr>
<td>Asia and Pacific</td>
<td>15-22 yrs</td>
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</table>

Developmental stage and readiness for transition may be better indicators than chronological age for determining when transition should occur.

 Disclosure of HIV status: prerequisite for transition to adult care

- Demonstrates understanding of his/her disease and its management
- Demonstrates the ability to take responsibility for their own treatment
- Aware about the importance of adherence to treatment
- Whenever possible, transition plan should be implemented when the patient’s disease is clinically stable

Davies MA JIAS 2017; Bailey H JIAS 2017

2. Developing a Transition Plan and Early Engagement of Patient/family in Discussion and Process

• The pediatric care provider
  – Collaborate with the patient and family to develop a transition plan with concrete goals and a timeline
  – Develop a written transition plan at least 1-3 years before the transition is planned
  – Update plan at least annually

NYS DOH: Transitioning HIV-infected adolescents into adult care
3. Individualized Assessment of Patient Readiness and Provide essential knowledge and skills for youth

- Knowledge of health conditions
- Clinical status and complications
- Medication management
- Preventive health behaviors
- Mental health, stigma
- Disclosure
- Responsible sexual activity and family planning
- Community resources
- Education vocation and career plans
- Family support
- Housing or goals for independent living
- Transportation, funding resources, health insurance

USAID tool kit for transition

Gilliam PP J Assc Nurses AIDS Care 2011, Bamford A HIV med 2015
4. Preliminary encounter with adult provider

Desirable characteristics for adult providers/clinic

- A single contact person assists in the transition
- Communication occurs between adolescents and adult providers during the transition process, adult clinic tour

Gilliam PP J Assoc Nurses AIDS Care 2011

- No stigma
- Easily accessible, convenient location
- One stop, comprehensive services (HTC, HIV/STI Rx, contraception, condom, lubricant, mental health, PrEP/PEP)
- Minimal charge (free)
- Competent friendly staff. Provide age/developmental appropriate care, respect youth sexual orientation
- Match with youth lifestyle (off-hour services)
5. Bilateral engagement of health care workers and multidisciplinary team

- Arrange meeting(s) between the patient, his/her adolescent practitioner and the new adult practitioner
- Engage a multidisciplinary team
- Identify a staff person at the clinic who is in charge of overseeing transition

Inter department case conference, Chiang Rai Prachanukroh Hospital, Thailand

Courtesy slide: Dr. Rawiwan Hansudewechakul
Chiang Rai Prachanukroh Regional Hospital
Adolescents can be successfully transitioned in a supportive process. Transitioning youth in groups (10-22): using a “camp” approach (1-2 days), meet with doctors and nurses in adult HIV clinics.

Introduce the adolescents to youth-friendly adult provider team, Siriraj hospital

**DVD: Transition to adult care (Happy Teen 2 Program)**

**Courtesy slide: Dr. Rawiwan Hansudewechakul Chiang Rai Prachanukroh Regional Hospital**

Hansudewechakul R et al. JIAS 2015

Dr. Peerawong Werarak
Department of Preventive and Social Medicine
Faculty of Medicine, Siriraj Hospital

I'll also ask about drug adherence and if they have any problem with taking ARV drugs.

However, before you're transferred to the adult clinic, we'll help you get ready.
6. Bi-directionality of communication and patient flow

Clinical summary letter

Complete the following review of each youth’s medical and social history and send to the Adult Provider who the youth will be transitioning to. This summary should be completed and shared with the young person so that they participate in the review of their history.

Client’s Name: ____________________________

Date: __________ Age: __________ Hospital Name or No.: __________

Date/Age at Diagnosis: __________

Medical History
Presenting Illness/Circumstances:

Subsequent Hospital Admissions/Serious Problems:

Other significant problems:

Progress in puberty:

Family History:

Developmental History:

Current Occupation: (In education/at work)

HIV Viral Parameters:

<table>
<thead>
<tr>
<th>Age/Date</th>
<th>CD4%</th>
<th>CD4 Count</th>
<th>Viral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Load</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presentation</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Nadir CD4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highest Viral Load</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Currently</td>
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<td></td>
<td></td>
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</tbody>
</table>

Resistance Tests

<table>
<thead>
<tr>
<th>Test</th>
<th>Age/Date</th>
<th>Type of Test</th>
<th>RT Mutations</th>
<th>PI</th>
</tr>
</thead>
<tbody>
<tr>
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Mutations:

Detailed Drug History
(ART & Prophylaxis, etc.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Reason for Start/Switch</th>
<th>Age/Date Started</th>
<th>Age/Date Stopped</th>
<th>Toxicities/Reactions</th>
</tr>
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The Thai Happy Teen I/II Model

Goals: to help adolescent living with HIV become a healthy, happy, coping, responsible adults

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Happy Teen 1 Early Teen</th>
<th>Happy Teen 2 Late Teen</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strategy 1: “Health Knowledge”</strong></td>
<td>HIV and STD knowledge</td>
<td>+ Transferring to adult HIV clinic</td>
</tr>
<tr>
<td><strong>Strategy 2: “Coping Skill”</strong></td>
<td>Self esteem and stress management</td>
<td>+ Communication skill</td>
</tr>
<tr>
<td><strong>Strategy 3: “Sexual Risk Reduction”</strong></td>
<td>Sexual and behavioral risk reduction</td>
<td>+ Disclosure to partner, stable sex partner</td>
</tr>
<tr>
<td><strong>Strategy 4: “Life Goal”</strong></td>
<td>Life skills and responsibilities</td>
<td>+ Education and career</td>
</tr>
</tbody>
</table>

**Happy Teen 1 Activities** *(Youth only)*

**Happy Teen 2 Activities** *(Youth + Caretaker)*

Lolekha R et al. JIAS 2017
Assessment of health-related knowledge of 161 perinatally HIV-infected youth participating in the Happy Teen 2 Program at baseline, 12, and 18 months, Thailand, 2015-2016

One year after the intervention, 36 youth transferred to adult clinic. 94% satisfied with the transition.
7. Peer engagement

Involving Young Adult Leaders as mentors can help transitioning youth be more successful

- Recruit volunteers
- Assess the suitability of the volunteers
- Orient Young Adult Leaders on their tasks
- Match youth and Young Adult Leader
- Develop supervision plan
- Build capacity of Young Adult Leaders to be mentors
- Building relationship with transition youth
- Provide support to youth transition

Transitioning HIV+ Youth From Adolescent to Adult Services Program. HRSA Oct 2010
8. Tracking individual and program outcomes

How to know if a youth has successfully transitioned?

Indicators
• % adherence to treatment regimen
• % appointments attended
• # of life skills achieved
• progression through the checklist

The Youth Exit Survey
Self-assess their transition experience based on:
• Satisfaction with the process
• Confidence in their ability to manage their own treatment plans

Transitioning HIV+ Youth From Adolescent to Adult Services Program. HRSA Oct 2010
Conclusions

• Increasing number of adolescents living with HIV and new HIV infections among adolescents
• Adolescents living with HIV faced many challenges
• Poor outcomes among youth living with HIV after transition to adult HIV care
• A well-planned transition to adult clinic (process, not an event) enables youth to assume adult roles and improving health outcomes
• The client/family/adult & pediatric providers should be involved in the process
• Coordination of health care, education, social services, health care coverage, and vocational services is essential
Future priorities for transition research and practice for adolescents living with HIV

- Optimal intervention strategies to reduce mortality and improve outcomes as the adolescent population expands and ages
- Longitudinal studies to effectively track and monitor physical and mental health outcomes of adolescents living with HIV
- Adolescent-friendly HIV healthcare services with comprehensive care to incorporate emerging co-morbidities and respect youth’s sexual orientation
- Broader health system reform and policies to ensure a holistic approach to HIV care (stigma, resources, equity access)
- Simple, standardized, decentralized guidelines, tools and materials for transition.
Thank you for your attention
Acknowledgements

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  – Queen Sirikit National Institute of Child Health (QSNICH), Thailand MOPH