Sex, Drugs and ART: Coming of Age with Perinatal HIV

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Coming of age with perinatal HIV

• The ‘Game of ‘Life’
• Expectations and challenges of the transition into adulthood
• Profile of youth with perinatal HIV: demographic, biomedical, mental health, behavioral characteristics
• Interventions to support youth and families
The Game of Life
Adolescence: transitioning from childhood to young adulthood

**Childhood**
- Dependence on parent/family/adults
- Adult supervision & decision-making
- Physical & emotional growth and development
- Education & learning
- No sex, substances (alcohol, drugs, cigarettes)
- Supervised healthcare (ART adherence)

**Adulthood**
- Full independence
- Education complete
- Employment
- Residential independence
- Marriage/Partner
- Pregnancy/parenthood
- Safe sex and substance use (alcohol, marijuana)
- Healthcare self-management (ART adherence)
Adolescence: a period of significant physical, cognitive, emotional & social change

- Physical growth & development, and brain maturation
- Separation/individuation from parents/family
- Peers increasingly important; social need to fit in with peers and feel ‘normal’
- Increased risk for non-adherence across all health conditions
- Presentation of psychiatric disorders, if at risk
- *Risk taking and experimentation*
  - Normative challenges around sexual and substance use behavior
Risky behavior and adolescence: Blame it on the brain

- Increase in morbidity and mortality during adolescence associated with rise in risk behaviors:

“The brain’s inhibitory system does not match the demands of the excitatory or sensation-seeking systems, resulting in increased participation in risky behaviors.” (Pharo, 2011)

- Limitations in executive function (cognitive processes associated with ability to carry out goal-directed behavior, impulse control, self-monitoring)

- Personality traits of impulsivity, sensation-seeking, aggression and sociability were related to increased levels of risky behavior (Pharo, 2011)
Consequences of ‘normative’ adolescent risk-taking in 3 critical domains

Health management
- Inadequate ART adherence
- Poor retention in care

Substance Use
- Pregnancy
- MTCT

Sexual Activity
- HIV transmission
- MDR HIV

HIV Disease Progression
Evolving profile of the pediatric epidemic: Youth with perinatal HIV
US pediatric HIV epidemic: Predominantly adolescent

- ~10,000 youth/young adults living with perinatally acquired HIV infection (CDC, 12/2008)
- NYC: 2,400 children with living with perinatal HIV (NYCDOH, 2011)
  - 13% < 13 years
  - 76% - 13-24 years
  - 11% > 24 years
Globally large numbers of HIV+ children are aging into adolescence

• Increasing numbers of children with perinatal HIV infection are surviving into adolescence
  ▪ Primarily attributed to the ART scale-up and improved case finding
• Efforts to prevent mother-to-child HIV transmission are increasingly more effective leading to fewer new infant infections
• The best available estimate is that approximately 2.2 million (6.5%) of the estimated 34 million people living with HIV in 2011 were 10–19 years old.
  ▪ Most countries with high burdens of HIV lack programmatic data on the size and characteristics of the HIV epidemic in young people with perinatal infection
Demographic profile of youth with perinatal HIV infection

• Globally, vulnerable families, typically affected by poverty, violence, limited health care and educational resources
• Disruptions in caregiving due to parental illness, death and poverty
• In some countries, parental substance abuse and untreated mental illness have decimated families
• In many countries, youth with perinatal HIV are from ethnic minorities and other disenfranchised populations who have coped with racism and discrimination, and now must cope with *HIV stigma*
Biomedical profile of youth with perinatal HIV infection

• Globally, youth with perinatal HIV have multiple health problems as a consequence of:
  – Suboptimal regimens during early childhood
  – Late identification and ART availability/initiation
  – Antiretroviral-associated toxicities

• Common health problems include: short stature; chronic lung disease; recurrent infections; neuro-cognitive impairment; cardiac disorders; osteoporosis; metabolic disorders; obesity

• Youth with perinatal HIV are also at high risk for treatment failure and multi-drug resistant (MDR)virus
# Lessons from US perinatal cohorts: *mental health, sex, drugs & ART adherence*

<table>
<thead>
<tr>
<th>Sites</th>
<th>Sites (NIMH, PI Mellins)</th>
<th>Baseline Age (Follow up Age)</th>
<th>Control Group</th>
<th>Method</th>
<th>Longitudinal</th>
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</thead>
<tbody>
<tr>
<td>CASAH</td>
<td>4 NYC,US</td>
<td>9-16 yrs (13-24 yrs)</td>
<td>Perinatally HIV-exposed, uninfected (PHIV-)</td>
<td>Interview</td>
<td>Yes</td>
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<tr>
<td>PHACS (NIH, PI Van Dyke; PI Seage)</td>
<td>12 US</td>
<td>7-16 yrs (10-18 yrs)</td>
<td>PHIV-</td>
<td>Interview</td>
<td>Yes</td>
</tr>
<tr>
<td>IMPAACT P1055 (NIAID, PI: Nachman)</td>
<td>29 US</td>
<td>7-17 yrs (8-20 yrs)</td>
<td>HIV-affected (PHIV- and HIV-)</td>
<td>Interview</td>
<td>Yes</td>
</tr>
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</table>
Youth with perinatal HIV:
Current psychiatric disorder

- **P1055** (Gadow, 2012)
- **CASAH** (Mellins, 2009, 2011)
- General Population (NCS-A, Kessler, 2012; n=10,148)
High rates of psychiatric disorders among HIV-infected and HIV-exposed uninfected youth

(Mellins, AIDS Care 2012; Gadow, J Dev Behav Ped, 2010)
Youth with perinatal HIV: Substance use

P1055 (Williams, 2010); CASAH (Elkington, 2009); PHACS (Mellins, 2011); General Population (2009 Youth Risk Behavior Systems Survey; YRBSS; n-15,425)
Youth with perinatal HIV: Sexual activity and sexual risk behavior

Onset of Sexual Activity

PHACS (10-18): 58% (42% No Risk, 16% Risk)
CASAH (14-18): 46% (54% No Risk, 4% Risk)
YRBSS (14-18): 53% (47% No Risk, 6% Risk)

Unprotected Sex Last Occasion

PHACS (10-18): 74% (26% No Risk, 48% Risk)
CASAH (14-18): 74% (26% No Risk, 48% Risk)
YRBSS (14-18): 61% (39% No Risk, 22% Risk)

PHACS (Tassiopoulos, 2011; Mellins, 2011); CASAH (Bauermeister, 2009); General Population (2012 Youth Risk Behavior System Survey; YRBSS)
Sexual activity and risk among youth with perinatal infection in Uganda

- 732 youth with perinatal HIV, 34% male, 15-19 years, from 4 districts in Uganda
  - Survey, Focus groups, In depth interviews
- 33% reported having had sex
  - Frequency of condom use:
    - 44% always, 32% sometimes, 16% rarely.
  - Currently using condoms to prevent:
    - 30% infecting partner; 25% HIV re-infection; 57% pregnancy
- Currently in a relationship (n=368)
  - 33% know current partner’s HIV status
  - 38% disclosed status to partner

(Birungi, J Adol Health, 2009)
Sexual risk behavior increases over time and with substance use

• In the CASAH cohort, as expected, the proportion of youth who were sexually active increased with increasing age.
  – The odds of having unprotected sex was more than twice as great at each additional follow-up visit.

• The odds of engaging in unprotected sex over time were over 4 times greater if youth reported using alcohol (AOR 4.19; 95% CI [2.08, 8.44], p < .001) and twice as great if youth used marijuana (AOR = 2.29; 95% CI [1.05, 5.02], p < .05), with no HIV group differences.

Elkington 2009, Bauermeiser, 2011
Viral resistance in sexually active youth with HIV RNA >5000 copies/ml (n=37), PHACS

- 42% of 92 sexually active ≥1 VL >5000 copies/ml
- 81% had resistance to ≥1 ARV class
- 24% had some resistance to drugs in all 3 classes
- 63% with resistance reported unprotected sex

Tassiopoulos et al. (2013)
Youth with perinatal HIV: Reported non-adherence past month

PHACS (Mellins, 2011; Usitalo, 2009); CASAH (Marhefka, 2009); P1055 (personal communication, Kacanek, 2013); Other illnesses (Bender, 2000; Johnson, 2002)

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<thead>
<tr>
<th>Group</th>
<th>No risk</th>
<th>Risk</th>
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<tbody>
<tr>
<td>PHACS (10-16 yrs)</td>
<td>34</td>
<td>66</td>
</tr>
<tr>
<td>P1055 (6-17 yrs)</td>
<td>32</td>
<td>68</td>
</tr>
<tr>
<td>CASAH (10-16 yrs)</td>
<td>57</td>
<td>43</td>
</tr>
<tr>
<td>CASAH (13-22 yrs)</td>
<td>62</td>
<td>38</td>
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<tr>
<td>Other illnesses</td>
<td>55</td>
<td>45</td>
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Lifetime adherence to ART – are we asking the impossible?

- Adherence is a formidable challenge to pediatric populations
  - Highly vulnerable to normal adolescent developmental
- Challenges of daily medication administration are accentuated during adolescence
- Adherence is not static: good today, gone tomorrow
- No perfect (and few good) measures of adherence
- Many are studying approaches to optimize ART adherence
Many youth with perinatal HIV exhibit great resiliency

Absence of Behavioral Health Risks (no psychiatric disorder, unprotected sex, substance use; non-adherence)
Les besoins psychosociaux des adolescents qui vivent avec le VIH
What can we do to support a safer passage through adolescence?

• HIV programs increasingly offer services to support youth with HIV including
  – Provision of mental health services
  – Peer-based activities: navigator, educators, groups, clubs
  – Counseling, education and outreach programs

• Few evidenced based interventions for this population

• In many countries there are studies in the field to evaluate a variety of interventions for HIV positive youth

• Interesting work in HIV prevention with adolescents including use of financial incentives – potential applicability to HIV-positive youth
CHAMP: Family-based mental health and HIV prevention program for uninfected older children and early adolescents

• Goal:
  – Strengthen the adult protective shield by improving parent-child relationships and communication and parent supervision skills and family support
  – Strengthen youth skills in problem solving, coping and negotiation of risky situations to reduce sexual and drug use behavior
  – Promote youth mental health

• Multiple families come together for 10 sessions, led by lay staff

• Curriculum and materials tailored to the specific context through collaborative work with community stakeholders

Mckay,; Bhana
CHAMP+ and VUKA

- CHAMP+: focus on promotion of ART adherence and mental health, and reduction of sexual and drug risk behavior
- Clinic-based, multiple-family groups, facilitated by lay staff
  10 session curriculum
  1) loss and bereavement, 2) ART adherence, 3) youth identity, 4) disclosure and coping, 5) adolescent development, 6) negotiating sexual possibility situations and peer pressure, 7) family communication, supervision, involvement, 8) stigma 9) social support
- Successful pilot RCTs in US, South Africa, Argentina
- Current large-scale RCT in South Africa (VUKA)cartoon-based curriculum; CHAMP+ASIA in Thailand & Indonesia

Mellins, Mckay
The VUKA Family

MA’ MAFUTHA   BAB’ VUKA   GOGO   MUZI   NONHLANHLA & NHLANHLA   SINDI
Surviving Loss and Bereavement

There is not very much room in Bab’Vuka’s house. Nono will sleep with Mamafutha. Themba will sleep on the sofa in the living room...

After everybody has gone to bed, Themba sits alone...

My life is changing...

My mother is gone. I’ve left Sbu and all my friends behind. And I’m staying with people I don’t even know...
MAMAFUTHA, THEMBA AND NONO GO IN TO SEE SISTER PATIENCE.

Today we are going to talk about your medication. Themba, do you have a good memory?

Yes, I think so...

That's good, because it's going to be very important for you to remember to take your medication every day.

Once you begin taking the medication, you have to take it every day. You must not miss a single day. If you forget to take it, even just once, it gives the virus a chance to reproduce itself more quickly.
Disclosure

THE NEXT DAY AT SCHOOL
Gogo makes me so mad. She treats me like a sick person.
Does she know your HIV status?

I wish I knew who knows, and who doesn’t know.

What’s that?

The problem of disclosure.

Who do you mean?

Sindi.

Does she suspect?

I don’t know. Maybe, maybe not.

Tell her then.

Do you trust her?

Of course.

And what about somebody who doesn’t know but you want them to know?

You have to disclose your status to certain people in your life. But you don’t want everyone to know. How do you stop those who do from telling those who don’t? It’s a problem.
Youth Identity

My father also died when I was small. Then my mother died too.

Now I'm an orphan. An Aids orphan.

That's not the only thing you are!

What do you mean?

You're also my new best friend!
Training curriculum for Adolescent Peer Educators

A Comprehensive Training Curriculum for Adolescent Peer Educators

PARTICIPANT MANUAL

TRAINER MANUAL

POSITIVE VOICES, POSITIVE CHOICES

ICAP
Columbia University Mailman School of Public Health
In Summary

• Rapidly emerging, substantial population of youth with perinatal HIV
  – Compromised health and mental health
  – Living with the demands of a chronic, multisystem, fatal, stigmatized disease
  – Grappling with complex psychosocial and behavioral issues
  – Traversing the rocky terrain of adolescence where risk taking and experimentation are normative behaviors

• Studies primarily from the US indicate high rates of mental health and adherence problems, & challenges related to initiation of sexual activity and substance use
  – Impact on long-term individual and public health outcomes

• Pressing need to study outcomes and interventions to successfully support this vulnerable population and ensure a safe passage into adulthood.
Special THANKS to Claude Mellins and the CASAH team, Chloe Teasdale, and the global community of providers and researchers working with youth living with perinatal HIV.