Promoting the Health and Behavioral Health of Adolescents Who Have Grown up with HIV

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Demographic Profile of Youth with Perinatal HIV Infection (PHIV+) (UNAIDS; CDC)

- 3.4 million children < 15 with HIV
- 2 million youth 10-19 yrs
- Globally, vulnerable families, typically affected by poverty, violence, limited health care and educational resources
- Disruptions in caregiving due to parental illness, death
- In some countries, parental substance abuse and untreated mental illness have decimated families
- In many countries, PHIV+ youth are from ethnic minority and other disenfranchised populations who have coped with racism and discrimination, and now must cope with HIV stigma
Adolescence, Risk & Resilience

- Research with PHIV+ youth has prioritized vulnerability and risk outcomes such as HIV transmission to others and non-adherence.
- Understanding risk is helpful in identifying problems for treatment or targeting vulnerable populations for prevention.
- Resilience = children who despite great adversity have successful outcomes.
- Understanding pathways to resilience has been helpful for defining the components of interventions most likely to promote positive youth development (Luthar, 2000; 2006).
- Both risk and resilience research important for informing needed efficacy-based interventions for PHIV+ youth.
- However, important not to lose sight of the every day tasks and goals that are part of normative development.
The Game of Life
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

HIV Disease Progression
SAFARI OF LIFE

Navigate your way through life and avoid the many hazards and pitfalls in order to find true success.

Brighter Futures Facilitator Handbook
Globally, multiple health problems due to
- Suboptimal regimens during early childhood
- Late identification or delayed access to treatment
- ART-associated toxicities

Common health problems associated with HIV or ART: cardiac, lung and metabolic disorders; bone and kidney disease; growth delays, obesity

Significant neurological effects of HIV particularly for those with early severe disease → neurocognitive delays and deficits

## Psychosocial/Behavioral Profile

### Lessons from 3 Longitudinal US Cohort Studies: Mental Health, Sex, Drugs, and ART Adherence

<table>
<thead>
<tr>
<th>Project, Funder, References</th>
<th>Sites</th>
<th>Baseline Age (Follow up Age)</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CASAH</strong>&lt;br&gt;(NIMH R01-MH069133; PI Mellins)&lt;br&gt;Mellins et al., 2009; 2011&lt;br&gt;Elkington et al., 2009; Bauermeister et al., 2009; 2012</td>
<td>4 NYC sites, US</td>
<td>9-16 yrs (13-24 yrs)</td>
<td>Perinatally HIV-exposed, uninfected (PHIV-)&lt;br&gt;Mellins et al., 2009; 2011&lt;br&gt;Elkington et al., 2009; Bauermeister et al., 2009; 2012</td>
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<td><strong>PHACS</strong>&lt;br&gt;(NIH: U01-HD052104: PI Van Dyke; U01-HD052102: PI Seage)&lt;br&gt;Mellins et al., 2011&lt;br&gt;Tassiopoulos et al., 2013&lt;br&gt;Alperin et al., in press&lt;br&gt;Usitalo et al., 2013</td>
<td>12 US sites</td>
<td>7-16 yrs (10-18 yrs)</td>
<td>PHIV-&lt;br&gt;Mellins et al., 2011&lt;br&gt;Tassiopoulos et al., 2013&lt;br&gt;Alperin et al., in press&lt;br&gt;Usitalo et al., 2013</td>
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<td><strong>IMPAACT P1055</strong>&lt;br&gt;(NIAID: U01-AI068632; PI: Nachman)&lt;br&gt;Gadow et al., 2010; 2012</td>
<td>29 US sites</td>
<td>7-17 yrs (8-20 yrs)</td>
<td>HIV-affected (PHIV- and HIV-)&lt;br&gt;Gadow et al., 2010; 2012</td>
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Youth with perinatal HIV

Current psychiatric disorder

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<thead>
<tr>
<th>Group</th>
<th>No Risk</th>
<th>Risk</th>
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<tbody>
<tr>
<td>P1055 (8-20 yrs)</td>
<td>39%</td>
<td>61%</td>
</tr>
<tr>
<td>CASAH (13-24 yrs)</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>NCS-A US (14-18 yrs)</td>
<td>40%</td>
<td>60%</td>
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Substance use

<table>
<thead>
<tr>
<th>Group</th>
<th>No Risk</th>
<th>Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>CASAH (10-16)</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>PHACS (10-16)</td>
<td>15%</td>
<td>85%</td>
</tr>
<tr>
<td>P1055 (12-18)</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>CASAH (14-18)</td>
<td>33%</td>
<td>67%</td>
</tr>
<tr>
<td>CASAH (16-20)</td>
<td>57%</td>
<td>43%</td>
</tr>
<tr>
<td>YRBSS (14-18)</td>
<td>72%</td>
<td>28%</td>
</tr>
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Unprotected Sex Last Occasion

<table>
<thead>
<tr>
<th>Group</th>
<th>No Risk</th>
<th>Risk</th>
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</thead>
<tbody>
<tr>
<td>PHACS (10-18)</td>
<td>58%</td>
<td>42%</td>
</tr>
<tr>
<td>CASAH (14-18)</td>
<td>46%</td>
<td>54%</td>
</tr>
<tr>
<td>YRBSS (14-18)</td>
<td>53%</td>
<td>47%</td>
</tr>
<tr>
<td>CASAH (14-18)</td>
<td>74%</td>
<td>26%</td>
</tr>
<tr>
<td>YRBSS (14-18)</td>
<td>61%</td>
<td>39%</td>
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Reported non-adherence past month

<table>
<thead>
<tr>
<th>Group</th>
<th>No Risk</th>
<th>Risk</th>
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</thead>
<tbody>
<tr>
<td>PHACS (10-16)</td>
<td>66%</td>
<td>34%</td>
</tr>
<tr>
<td>P1055 (6-17 yrs)</td>
<td>68%</td>
<td>32%</td>
</tr>
<tr>
<td>CASAH (10-16 yrs)</td>
<td>43%</td>
<td>57%</td>
</tr>
<tr>
<td>CASAH (13-22 yrs)</td>
<td>38%</td>
<td>62%</td>
</tr>
<tr>
<td>Other illnesses</td>
<td>45%</td>
<td>55%</td>
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International Studies Show Similar Rates

- **Mental health problems** (Zambia; Menon, 2007; Thailand; Lee, 2011)
  - 28%- 48%

- **Sexual Behavior** (Uganda: Birungi, 2009)
  - 33% sexually active (15-19 yrs);
  - 53% of whom currently did not use condoms

- **Substance Use** (Thailand/Malaysia: Prasitsuebsai, 2012; Lee, 2009)
  - 19%- 24% alcohol (10-18 yrs)

  - 50% - 58% (0-15 yrs)
  - Only 20% of youth achieved 100% adherence by pharmacy refill data at 6 months (Nachega et al., 2009)
What can we do to support a safer passage through adolescence?

- **THERE IS NOT 1 MAGIC PILL**, Nor one factor that makes people engage or not engage in health behaviors.
Models of Risk and Resilience

- Parent-child relationships, warmth & support, communication, supervision, monitoring
- Development, puberty
- Problem solving, self-efficacy, affect regulation, negotiation skills
- Health & CNS outcomes, Provider-patient relationship
- Poverty, violence, life events, conversely-community supports
What can we do to support a safer passage through adolescence?

- Although there are many clinical efforts to support health and behavioral health, few evidence based interventions for this population exist
  - Present two: CHAMP+ and SUUBI+
  - They each target different individual, family or contextual factors shown to be associated with positive youth development in other populations
CHAMP+

- CHAMP+ (for PHIV+ youth): focus on ART adherence, sexual risk behavior and mental health

- Based on CHAMP (NIMH: McKay, 2000; Bhana, 2010)

- Similar to CHAMP Goal: promote POSITIVE YOUTH DEVELOPMENT by
  - Strengthening the adult protective shield by improving parent-child relationships, communication and supervision skills, and family support
  - Strengthening youth skills in problem solving, coping and negotiation of risky situations
  - Promoting youth self-esteem and mental health

- Premise is that skills families need to monitor and support youth around sexual risk are similar to those needed to promote adherence to treatment

- Similar CHAMP, CHAMP+ Curriculum and materials tailored to the specific context through collaborative work with community stakeholders
CHAMP+ and VUKA
(NIMH, NICHD, NINR; Victor Daitz Foundation, WALDO Foundation, Columbia University’s MTCT plus/ICAP program)

- Similar structure retained with multiple-family groups, 10 session curriculum, facilitated by lay staff

- Changes: Clinic based; name changed in South Africa to VUKA

- **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, 8) supervision, involvement, 9) stigma, 10) Social support

- Successful pilot in 2 hospitals in South Africa, with improved adherence to treatment and mental health
  (Bhana, 2010; Mellins, 2012; McKay, 2012)

- Current large-scale RCT in South Africa (Mckay, Bhana, Mellins)
The Vuka Family

MA’ MAFUTHA  BAB’ VUKA  GO.GO  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 S’bu and all my friends behind. And I’m staying with people I don’t even know.
Adherence

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 day. If you forget to take it, even just once, it gives the virus a chance to reproduce itself more quickly.
The next day at school.

Gogo makes me so mad. She treats me like a sick person.

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

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

Does she know your HIV status?

I don’t know. Maybe...

What’s that?

Does she suspect?

I don’t know. Maybe, maybe not.

Do you trust her?

Of course.

Tell her then.
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!
SUUBI+ Adherence
(NICHD; PI: Ssewamala; Co-I: Mellins, McKay)

- Unfortunately many behavioral interventions do not have long term effects
- Adherence remains an elusive outcome and a major barrier to actualizing the full potential of medical advances
- Beginnings of SUUBI+ Adherence- RFA and Fred Ssewamala question:
  - Is poverty a primary barrier to ART adherence for youth?
  - Can an economic empowerment intervention improve adherence?
- Economic inequalities and substantive impoverishment have been thought to influence access, but not necessarily daily adherence.
SUUBI
Economic empowerment of adolescents in Sub-Saharan Africa (PI: Ssewamala)

- **Designed for:** uninfected orphans and vulnerable children
- **Goal:** promote health and mental health, reduce sexual risk behavior
- **Method:** improve capacity for economic stability of child, family and community
- **Working with local banks and families to teach youth about savings and loans, and vocational skills**

1. **SEED Pilot Study** (The Friedman Family Foundation; CU; CSD); 2. **SUUBI (Hope) Project** (NIMH); 3. **SUUBI-Maka Project** (NIMH); 4. **Bridges to the Future – R01 (Uganda)** (NICHD)
In Uganda: focus groups with HIV+ youth & their caregivers

- Poverty-related factors were the primary barriers to ART adherence:
  - food insecurity vs need to take some medicines with food;
  - school fees vs ART;
  - Work vs clinic visits.

Developed SUUBI+: Goal: to improve ART treatment adherence, while reducing risk behaviors and improving mental health and economic stability

1. Family-based asset-building and promotion of education
2. Clinic support using VUKA HIV treatment adherence materials

RCT with PHIV+ youth (10-16 yrs) in 32 clinics in 3 Districts
In Summary

- Rapidly emerging, population of youth with perinatal HIV
  - Living with the demands of a chronic, stigmatized illness
  - Grappling with complex medical, psychosocial and behavioral issues in contexts of significant low resources and economic inequality
  - Traversing the rocky terrain of adolescence where risk-taking and experimentation are normative behaviors

- Pressing need for interventions that promote normative development and successful transition to adulthood under challenging circumstances

- Need Interventions that address the multiple individual, family and contextual factors that influence behavior long term, including those that support the financial stability of youth and give them a future vision.
The question is not whether we can afford to invest in opportunities for [PHIV+ adolescents] but how we can possibly afford not to.

Adapted from Nicholas D. Kristoff-
1/31/2013

NY Times Op-Ed
It Takes A Village: Collaborators

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Youth living with HIV and their families who gave us their time and wisdom

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