Ongoing Follow-up of Perinatally HIV-infected Children into Adolescence: The Need for an Integrated Approach

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Pediatric HIV
Is Now An Adolescent Epidemic

- US: nearly 10,000 youth/young adults living with perinatally acquired HIV infection (CDC, 12/2008)

- NYC: 2,499 children dx < 13 years who are still living with HIV (NYCDOH, 2011)
  - 98% perinatal HIV infection (PHIV+)
  - 13% < 13 years
  - 76% = 13-24 years
  - 11% > 24 years

- Global: 3.3 million children < 15 years living with HIV (UNAIDS; 12/2011)
Adolescence, Risk & Resilience

- **Adolescence is a period of challenge**: Significant physical, cognitive, emotional and social changes.

- "**Adolescence is an age of opportunity** for children, and a pivotal time for us to build on their development... to help them navigate risks and vulnerabilities, and to set them on the path to fulfilling their potential" *(UNICEF, 2011)*

- Research with PHIV+ youth has prioritized identifying risk, namely poor health and behavioral outcomes.

- Understanding risk is helpful in identifying problems for treatment and targeting vulnerable populations for prevention efforts.
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)

As PHIV+ children across the globe reach adolescence and young adulthood → Urgent need for both risk and resilience research to inform efficacy based interventions
Why Are Youth with Perinatal HIV-Infection at Risk?

- Globally: vulnerable families, typically affected by poverty, violence, limited health care resources
- In some countries, exposure to parental substance abuse and untreated mental illness has decimated families
- Disruptions in caregiving for children due to parental substance use, illness, and death
- In many countries, youth born with HIV are from disempowered or ethnic minority families who have coped with racism and discrimination, and now must cope with HIV-stigma

(Boyd-Franklin, 1994; Domek, 2006; Havens & Mellins, 2008; Kapetanovic, 2009; Malee, 2013; Mellins, 1997, 2000, 2003; Ng, 2004; Palmer, 2011; Santamaria, 2012)
Why Are Youth with Perinatal HIV-Infecion at Risk (cont.)?

- Experienced multiple environmental and social stressors
- In some countries: genetic and environmental risk for substance abuse and mental health problems
- Experienced an extended period of less than optimal treatment (pre-HAART) → health and neurocognitive effects
- Aging into developmental stage of
  - Presentation of psychiatric disorder (if at risk)
  - Normative challenges related to experimentation with sexual and substance use behavior
  - Social need to fit in with peers and feel “normal”
  - Increased risk for non-adherence across conditions
Neurodevelopmental and cognitive deficits, including encephalopathy
(Boivin, 2010; Brouwers, 1994; Chiroboga, 2005; Drotar, 1999; Nozyce, 2006; Smith, 2006, 2009, 2012; Puthanakit, 2010; Van Rie, 2011; Wolters, 2005)

While ART reduces encephalopathy- cognitive problems are still found even with adequate viral control
(Chriboga, 2005; Lyon, 2009)

High rates of emotional and behavioral problems, particularly anxiety, ADHD, and depression
(Havens, 1994; Moss, 1996; Mellins, 2003; Malee, 2011; Sharko, 2006; Lee, 2011)

High rates of non-adherence to medication
(Rudy, 2010; Usitalo, 2010; Van Dyke, 2002; Williams, 2006; Malee, 2011; Nichols, 2012)
<table>
<thead>
<tr>
<th>Study</th>
<th>Sites</th>
<th>Baseline Age (Follow up Age)</th>
<th>Control Group</th>
<th>Method</th>
<th>Longitudinal</th>
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<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</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</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>
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<tr>
<td>LEGACY</td>
<td>22 US</td>
<td>0-24 yrs (13-24 yrs)</td>
<td>None</td>
<td>Chart Review</td>
<td>Yes</td>
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</tbody>
</table>
PHIV+ Youth: Current Psychiatric Disorder

P1055 (Gadow, 2012); CASAH (Mellins, 2009, 2011); LEGACY (Kapetanovic, 2011); General Population (NCS-A, Kessler, 2012; n=10,148)
PHIV+ Youth: Substance Use

P1055 (Williams, 2010); CASAH (Elkington, 2009); PHACS (Mellins, 2011); General Population (2009 Youth Risk Behavior Systems Survey; YRBSS; n=15,425)
PHIV+ Youth: Sexual Risk

Onset of Sexual Activity

PHACS (10-18) 58%
PHACS (14-18) 46%
YRBSS (14-18) 53%

Unprotected Sex Last Occasion

CASAH (14-18) 74%
YRBSS (14-18) 61%

PHACS (Tassiopoulos, 2011; Mellins, 2011); CASAH (Bauermeister, 2009); General Population (2012 Youth Risk Behavior System Survey; YRBSS)
PHIV+ Youth: Non-Adherence in the Past Month

PHACS (Mellins, 2011; Usitalo, 2009); CASAH (Marhefka, 2009); P1055 (personal communication, Kacanek, 2013); Other illnesses (Bender, 2000; Johnson, 2002)
Difficult to present comparable data: fewer studies, particularly on adolescents and young adults, different age ranges, diverse measures and study variables

Mental health problems:
- 48% (Italy [CBCL]; Bomba, 2010)
- 30% (Zambia [SDQ]; Menon, 2007)
- 28% (Thailand [CDI]; Lee, 2011)

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

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

ART Non-adherence
- 50% - 58% (0-15 yrs) (Togo: Polisset, 2009; Kenya: Vreeman, 2010; Rwanda: Kikuchi, 2012)
Absence of Behavioral Health Risks (no psychiatric disorder, unprotected sex, substance use; non-adherence)

PHACS Baseline (10-16 yrs)
- Risk: 42%
- No Risk: 58%

CASAH Follow-up (13-24 yrs)
- Risk: 39%
- No Risk: 61%

LEGACY (13-21 yrs)
- Risk: 26%
- No Risk: 74%

PHACS and CASAH (Mellins, 2011, 2013); LEGACY (Kapetanovic, 2011)
Models of Risk and Resilience

Parent-child relationships, communication, supervision, monitoring

Adolescence

Family Systems

Medical/Psychosocial Support

Self-Regulation

Environment & Life events

Behavioral Health

Peers/support systems

Problem solving, coping, negotiation, life skills

Health & CNS outcomes, Provider-patient relationship

Poverty, violence, life events, conversely-community supports
What does this mean for interventions?

- THERE IS NOT 1 MAGIC PILL, Nor one factor that makes people 1) take pills, 2) delay sex, 3) use condoms, 4) not use drugs
The National Institutes of Health (2006) noted that effective behavioral interventions

- Intervene at multiple system levels
- Simultaneously target multiple risk factors
- Integrate behavioral interventions into the environment

Many service programs across the globe are attempting to do this.

Unfortunately few have been systematically evaluated, few evidence-based interventions
In high resource countries - model of Psychosocial Services for HIV-affected Families

- One stop shopping
  - Adults & children treated in the same site
  - Mental health services by professional staff integrated with medical services
  - Multidisciplinary services delivered in a coordinated manner
  - Expensive and may be difficult to scale up
Two examples of evidence-based interventions that target multiple systems, multiple outcomes, and can be delivered by lay staff and are being evaluated in large scale trials in Africa

- CHAMP+/VUKA
- SUUBI+ Adherence
CHAMP: Family-based mental health and HIV prevention program for uninfected older children and early adolescents

Developed and tested in large scale trials in the US, with successful adaptations and RCTs in South Africa and Trinidad

Goal: promote RESILIENCE by

- Strengthening the adult protective shield by improving parent-child relationships and communication and parent supervision skills and family support
- Strengthening youth skills in problem solving, coping & negotiation of risky situations to reduce sexual and drug use behavior
- Promoting 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
CHAMP+ and VUKA
(NIMH, NICHD, NINR; Victor Daitz Foundation, WALDO Foundation, Columbia University’s MTCT plus/ICAP program)

- **CHAMP+ (for PHIV+ youth):** 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 (Bhana, 2013; Mellins, 2012; McKay, 2013); **Pilot work in Thailand**

- Current large-scale RCT in South Africa (VUKA)- Cartoon-based curriculum
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 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.

The problem of disclosure.

What's that?

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.

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

Who do you mean?

Sindi.

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
Economic empowerment of adolescents in Sub-Saharan Africa (PI Ssewamala)

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

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)
SUUBI+ Adherence
(NICHD; PI Ssewamala; co-I Mellins, McKay)

- RCT with PHI+ youth (10-16 yrs)
- 32 clinics in 3 Districts of Uganda randomized to intervention vs Standard of Care
- Goal: to improve ART treatment adherence, while reducing risk behaviors and improving mental health and economic stability
  1. Family-based asset-building
  2. Clinic support using VUKA HIV treatment adherence materials
Conclusions

- **Risk**: Studies indicate high rates of mental health and adherence problems, & challenges related to normative experimentation with sex & substance use
  - Need for interventions that target multiple behavioral health outcomes (none to date have been fully tested)

- **Resilience**: Data also suggest relatively high rates of resilience, but few studies have used a resilience framework in PHIV+ youth

- **Paradigm shift**: Need to understand population specific pathways to resilience, and the modifiable protective factors to help support those who are most vulnerable

- **Go where the epidemic is**:
  - Conduct cross-cultural studies
  - Develop evidence-based interventions that are effective, acceptable, accessible, affordable and scalable
…… is not whether we can afford to invest in opportunities for PHIV+ children and 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

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It Takes A Village: Collaborators

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