Working with Children/Adolescents with or affected by HIV/AIDS

Jennifer Cruz, Ph.D.
Clinical Psychologist
Special Needs Clinic, NYP/Columbia
Overview and Objectives

- Current Statistics on Pediatric HIV/AIDS
- MH, Neurocognitive, and Developmental Impact of HIV on Children and Adolescents
- Clinical Challenges and Recommendations with HIV and Youth
Figure 1. Perinatally HIV-infected Children (N=3,901), by Year of Birth and Vital Status, 1977–2008, NYC

The number of HIV-infected infants born each year decreased dramatically from the peak in 1990. This coincides with the use of perinatal prevention measures.
Figure 4. HIV-exposed Births in New York City, 1988–2008

Number of HIV-exposed children born in NYC from NYS HIV testing data (line) is compared with the number reported through special projects to the NYC DOHMH from NYC E-PHAS sites (bars). During 2005-2008, 65% of NYC HIV-exposed births were born at E-PHAS sites. The number of infected infants has dropped dramatically.
The majority of perinatally HIV-infected children diagnosed during 2001-2008 resided in the Bronx and Brooklyn; the majority of children are black or of Hispanic ethnicity.
This figure includes all pediatric cases (98% were infected through perinatal transmission). 79% of HIV-infected children have survived into adolescence and young adulthood.
Overview and Objectives

- Current Statistics on Pediatric HIV/AIDS
- MH, Neurocognitive, and Developmental Impact of HIV on Children and Adolescents
- Clinical Challenges and Recommendations with HIV and Youth
Different Populations, Different Issues

- Groups
  - Perinatally HIV Infected Youth
  - Behaviorally HIV Infected Youth
  - Youth At Risk
  - HIV Affected youth

- Considerations
  - Contextual Factors
  - Neuropsychiatric Issues
  - Psychiatric Disorders
<table>
<thead>
<tr>
<th>Considerations by Population</th>
<th>Perinatal</th>
<th>Behavioral</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infected</strong></td>
<td><strong>Perinatally Infected</strong></td>
<td><strong>Behaviorally Infected</strong></td>
</tr>
<tr>
<td></td>
<td>Disclosure</td>
<td>Stigma</td>
</tr>
<tr>
<td></td>
<td>Adherence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death of Parents</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Foster/Adoption Care</td>
<td>Risk Behaviors</td>
</tr>
<tr>
<td></td>
<td>Illness of Parents/Self</td>
<td>Substance Use</td>
</tr>
<tr>
<td></td>
<td>Mental Health</td>
<td>Environment</td>
</tr>
<tr>
<td></td>
<td>Neuropsych</td>
<td>Mental Health</td>
</tr>
<tr>
<td><strong>Exposed/Risk</strong></td>
<td><strong>Perinatally Exposed</strong></td>
<td><strong>At-Risk Youth</strong></td>
</tr>
<tr>
<td></td>
<td>Death of Parents</td>
<td>Prevention</td>
</tr>
<tr>
<td></td>
<td>Foster/Adoption Care</td>
<td>Risky Behaviors</td>
</tr>
<tr>
<td></td>
<td>Illness of Parents</td>
<td>Mental Health</td>
</tr>
<tr>
<td></td>
<td>Family Stress</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental Health</td>
<td></td>
</tr>
</tbody>
</table>
Mental Health Issues

- Higher Rates in All Groups
  - Genetic Predispositions
  - Environment
  - Joint Risk
- Interactive with Poor Health Outcomes
- Substance Use Common (Behavioral)
- Intergenerational Problems
HIV-1 is Neurovirulent
- **Direct:** Invasion of CNS cells
- **Indirect:** Immune Activation

Neuropsychiatric Effects

(McArthur et al, 2010)
Perinatally Infected Neuropsychiatric Effects

- Developmental Problems
  - Cognitive delays
  - Speech and language delays (exp>receptive)
  - Motor delays
  - Social skills delays

- Confounded/Worsened by
  - Prenatal drug/alcohol exposure
  - Malnutrition

- Prenatal ARV exposure does not have long term effects.
Impact of AIDS diagnosis on neurocognitive and psychiatric outcomes

- Children's Hospital of Philadelphia
- 81 perinatal HIV + adolescents
- 47% had an AIDS defining dx
- 48% had a psychiatric diagnosis
- 30% had a mood disorder

<table>
<thead>
<tr>
<th></th>
<th>AIDS</th>
<th>Non AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>FSIQ</td>
<td>82</td>
<td>93</td>
</tr>
<tr>
<td>LD</td>
<td>60%</td>
<td>25%</td>
</tr>
<tr>
<td>Psy Dx</td>
<td>60%</td>
<td>37%</td>
</tr>
<tr>
<td>Psy Meds</td>
<td>38%</td>
<td>23%</td>
</tr>
<tr>
<td>ADHD</td>
<td>16%</td>
<td>21%</td>
</tr>
<tr>
<td>Psychotic</td>
<td>18%</td>
<td>0%</td>
</tr>
<tr>
<td>Mood</td>
<td>42%</td>
<td>21%</td>
</tr>
<tr>
<td>Psy Hosp</td>
<td>26%</td>
<td>7%</td>
</tr>
</tbody>
</table>
Contextual Factors: Perinatal Exposure

- Ethnic Minority Status
- Poverty
- Psychosocial Adversity
- Intergenerational Mental Illness/Trauma
- Substance abuse/Prenatal Drug exposure
- Low Birth Weight, Prematurity

- Both HIV infected and affected youth have greater risk for poor outcomes
• Current Statistics on Pediatric HIV/AIDS

• MH, Neurocognitive, and Developmental Impact of HIV on Children and Adolescents

• Clinical Challenges and Recommendations with HIV and Youth

Overview and Objectives
A Changing Landscape
Navigating Adolescence with HIV

- Disclosure (self-other)
- Reduce Risky Behaviors
- Treat Mental Health Issues
- Develop Social Support
- Cope with Stigma
- Healthy Sexuality
- Adherence
- Transition into Adulthood
Adherence in Youth

“If we can keep them alive until they are 25, we did it”
-Pediatric HIV Medical Provider
Adherence in Adolescence

- Invincibility vs. Inevitability
- Individuation
- Identity
- Anger/Emotions
- Pill Burden
- Desire to Forget
- Long Term Planning
- Developing Brain
Adolescence

Family Systems

Medical

Mental Health

Environment

Life

- Supervision & monitoring
- Autonomous strivings
- Caregiver treatment adherence

- Autonomy
- Peer relationships
- Self-Identity

- Neighborhood poverty
- Stigma

- Stressful life events
- Daily routine

- ARV side effects
- Poor virologic/ immunologic functioning

- Depression
- Cognitive delays
Improving Adherence

• Individuality
  ◦ Get it.
  ◦ Find what matters

• Support
  ◦ Normalize
  ◦ Parental Support
  ◦ Find a Community

• Go Light on the ‘Scare Tactic’
Transitioning to Adult Care
Barriers to Transitions

- Cognitive Impairments
- Developmental Skills
- Psychosocial Stressors
- Normative Changes
- Integration of Services
- Stigma
• Reduced Adherence (both care/meds)
• Increased Viral Load
• Lower CD4’s
• Increased Psychiatric Distress
• Delayed transitions

Transition Challenges
“When you turn 20, everyone just stops doing everything for you. I had no idea what adults used to do for me.”

-PHIV patient, age 23
Improving Transitions

- Continuity
- Logistics
- Communication
- Developmental Level
- Interdisciplinary Team
- Pediatric Providers Plan
- Adult Providers Adapt
HIV infected youth are emerging young adults with interrelated issues
- Resistance/AIDS
- Neurodevelopmental Issues
- Psychiatric Distress

Successful Care Is:
- Developmentally Sensitive
- Integrated
- Focused On Transitions

Summary: Moving Forward