They are not kids anymore
Standing at the crossroads of adolescent HIV Care

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From adolescent to adult

• Global and regional epidemiology
• Disease and treatment outcomes
• Transitions in care and post-transition outcomes
Big picture

• 2M adolescents (10-19) with HIV
  – >80% in sub-Saharan Africa*
  – Two-third of new infections in females**
• 4.3M young adults (15-24) with HIV**
• Percentage of perinatal infections unclear
• ~600,000 children to “age out” between 2015 and 2020

Adolescents and young adults represent a mix of populations

- Perinatally infected have unique chronic health problems and long-term HIV management needs
  - Neurocognitive outcomes, mortality
  - Rarely on the global policy radar

- Behaviorally infected coping with new infections, frequently from high-risk populations
  - Social instability, mental health, linkage/retention
  - Focus of current policy initiatives
    - UN-led All in, PEPFAR DREAMS
Adolescents *living* with HIV, 2014
N=824,374 (10-14) + 1,179,480 (15-19)

UNAIDS 2014 estimates.
*First number refers to ages 10-14 years and second number to ages 15-19 years.*
TREAT Asia Pediatric HIV Observational Database (TApHOD), N=5783

First clinic visit by year
Age at last visit, TApHOD, 2015

- 5783 patients in database
- Median age 11 (IQR 7.0-15.2) years
  - 49% female
- Mortality 9%
- Loss to follow-up 5.7%
- Transfers 24%
Viral suppression, treatment failure

• Global review of viral suppression, 20 studies¹
  – 21-100% (N >2784) with test; 27-89% suppressed

• 1st-line outcomes²
  – Southeast Asia: perinatal (N=534; 2176 PYS), NNRTI start at ≥10 yrs; 18% (4.4/100 PYS) with failure → switch over 3.6 yrs

• 2nd-line outcomes
  – Thailand (N=111): 41% with VL >400 by 24 mths³
  – Thailand, Vietnam, Indonesia (N=277): 27% (7.25/100PYS) with VL >1000 over 3.3 yrs⁴

Comorbidities – Mixed picture

• Cardiovascular disease
  – US adolescents with lower nadir CD4 and higher current viral load with poorer cardiac function\(^1\)
    • Lower LV contractility and fractional shortening z scores
  – Thai adolescents with similar cardiac function and cIMT to controls; 52% with hypertriglyceridemia\(^2\)

• Bone health
  – 16% of virally suppressed Thai and Indonesian perinatally infected adolescents with lumbar spine BMD Z-score \(<-2\) (N=396)\(^3\)

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3) Sudjaritruk, HIV Medicine, in press. cIMT-carotid intima-media thickness.
Most prevalent mental health conditions among perinatally infected US youth, N=294 IMPAACT P1055 cohort

Kacanek D, AIDS, Jun 2015.
Adolescents dying with HIV, 2014
N=32,118 (10-14) + 27,709 (15-19) = 59,827

UNAIDS 2014 estimates.
First number refers to ages 10-14 years and second number to ages 15-19 years.
Global Burden of Disease Study
HIV and Adolescents, 10-19 years

• #2 cause of death
  – 75,564 (95% UI 69,254-82,629) deaths
  – Rates decreasing for all other infectious causes

• #6 cause of disability-adjusted life years
  – 5.6M lifetime DALYs
  – Only infectious cause in the top 10

Vos T, GBD Pediatrics Collaboration, JAMA Peds, Jan 2016. Study used 2013 data.
UI-uncertainty interval
What we think we know

- Perinatally infected adolescents are aging up, while new infections are continuing among youth
- Health and program outcomes can be worse than for adults, but regional data vary*
  - Medical complications and treatment fatigue
  - Low rates of viral suppression, problems with retention
- Serious concerns over global mortality data

*Worse
US. Yehia BR, JAIDS, Apr 2015.

*Better
Adolescent cascade and continuum

Transitions in...

• Healthcare
  – Clinics and providers
    • Peds → adult
    • Peds → adolescent → adult
    • Adolescent → adult

• Development
  – Child → adolescent → young adult

• Responsibility
  – Caregiver → patient

“Gee. I had hoped to make it to the adult table at Thanksgiving before you recommended I have my first colonoscopy.”
Adolescents are dealing with:
- Adherence
- Disclosure
- Drugs
- Employment
- Finances
- Gender identity
- Housing
- Mental health
- Peers
- School
- Support networks
- Retention…

Children
Dependent

Adults
Independent
Transition in the context of HIV

- Greater social vulnerability
  - Limited parental support, financial resources
  - Perinatal and behavioral infection
  - Key populations

- Differences by healthcare systems*
  - Family clinics: *Integration*
  - Specialist clinics: *Transfer* to youth or adult clinics

*Foster C, CHIVA Guidance on transition for adolescents living with HIV, 2011.
What is successful transition?

- Adolescents
  - Accepted their chronic illness and oriented toward future goals and hopes, including long-term survival.
  - Learned the skills needed to negotiate appointments and with multiple providers in an adult practice setting.
  - Achieved independence and are able to assume responsibility for their treatment and participate in decision-making.
  - Practiced life skills (e.g., educational goals, job training, and parenting).
  - Receive uninterrupted comprehensive medical care.
- Pediatric and adult providers are familiar with each other, and directly communicate about an individualized plan for the patient.
- Mental health services have been transitioned at the same time as medical services.
- Psychosocial needs are met and entitlements are in place (housing, health insurance, home care, transportation).
Mortality in HYPnet, UK

11 deaths among 248 transfers at 14 UK NHS clinics, 2003-2011

- Age 21 (IQR 17-24) years
- CD4 27 (range 0-630) cells/mcl
- 5 on ART
- 7 in school or working
- 7 living with parents
- 9 with mental health problems
- 9 accessing peer support

Transition outcomes, Thailand

Chiang Rai, Thailand (N=67; 2008-2015)
Transfer to same-site adult HIV clinic
1 to >6 years post-transition

Hansudewechakul R, JIAS, Dec 2015.
How do we improve adolescent and transition outcomes?

• Strengthen adolescent clinical services
  – Providers comfortable and skilled with adolescents
  – Greater flexibility for appointments
  – Peer support

• Enhance coordination between providers
  – Leadership and advocacy
  – Provider to provider sharing of information beyond basic medical records
    • Family relationships, social issues, learning/school performance, future goals, risk behaviors
How do we improve adolescent and transition outcomes?

• Support the patient/family
  – Listen to adolescents and young adults
  – Learn from prevention and other chronic disease research
Combination social protection

• Financial and other support to improve health
  – **Cash incentives**: Reward healthy decision-making
    • Cash for negative STI testing
  – **Conditional cash transfers**: Incentivize specific behaviors to reduce structural drivers of risk
    • Cash for attending school
  – **Social protection**: Mitigate structural deprivations
    • Food vouchers, family/teacher support, social welfare grants

• Impact varies by population + intervention type, access, and uptake

Impact of cash + care on HIV risk behaviors in South African adolescents

% of girls and boys with 1+HIV-risk behavior at 1-year follow-up (n=3500, South Africa)

- **Girls**
  - No support: 41%
  - Cash: 42%
  - Cash plus care: 15%

- **Boys**
  - No support: 28%
  - Cash: 25%
  - Cash plus care: 17%

Cluver LD, JIAS, Dec 2015.
Summary

- Adolescents represent a growing and complex population at high risk of treatment complications

- As they transition to adult life, they need support to adjust to changes in their HIV care
  - Personal: Family, providers, peers
  - Structural: Healthcare systems

- Future research should track both clinical and social outcomes
  - Pediatrics + adult medicine