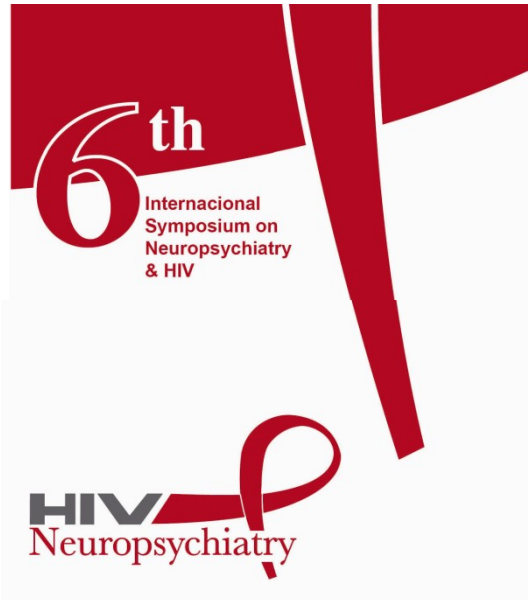
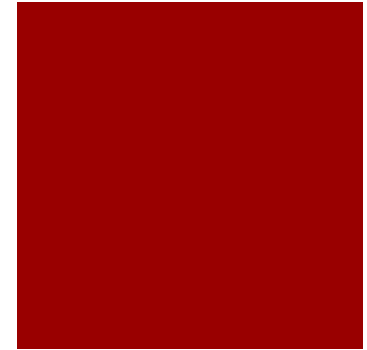




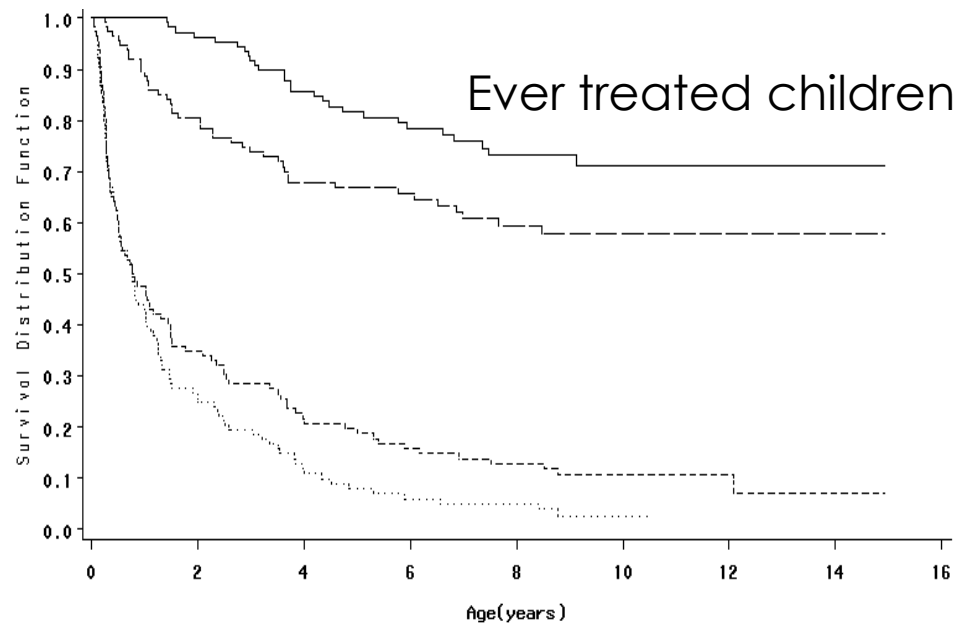
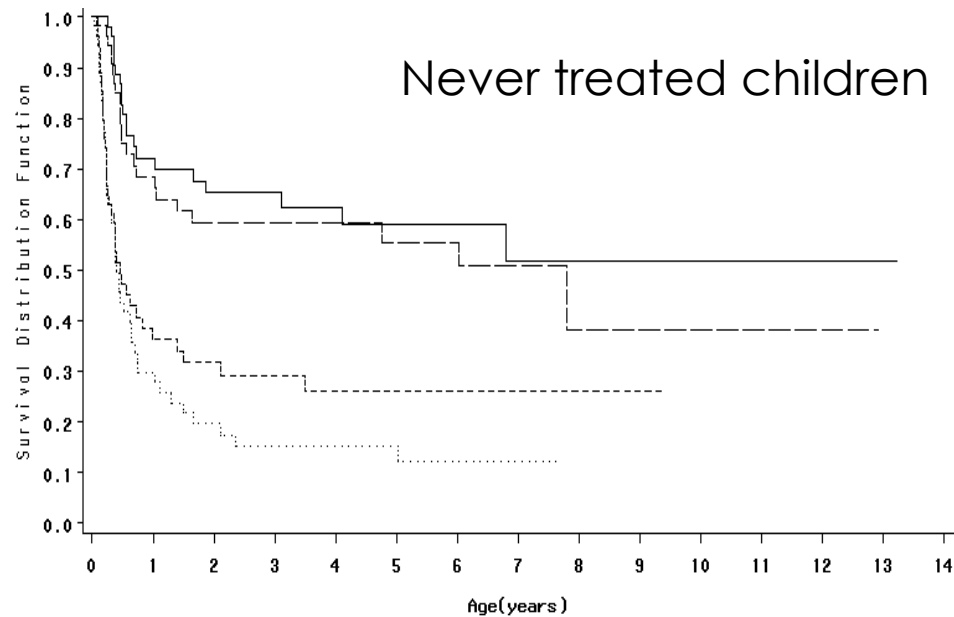
Adolescents. Management of HIV Infected Adolescents as They Get Into an Adult Outpatient Clinic

Clàudia Fortuny Guasch/Antoni
Noguera Julian
Unitat d'Infeccions. Hospital Sant Joan de
Déu. UB

HIV infected adolescents



- Vertically-HIV-infected adolescents:
 - Most patients are symptomatic:
 - Direct HIV-related cytopathic effect
 - Secondary to immune suppression
 - Up to 30-40% of patients with an AIDS diagnosis
 - HIV encephalopathy... but also mild delays in specific neurocognitive areas
 - Delayed puberal development
 - Body fat redistribution associated with ART use
- Non-progressors are only 2,4%
- Mild symptomatic patients: 6-15%



Progression

Cumulative % progressing to C or death:

Untreated: age 1 year: 30%

5 yrs: 43%

10 yrs: 61%

Treated: age 1 year: 12%

5 yrs : 33%

10 yrs: 43%

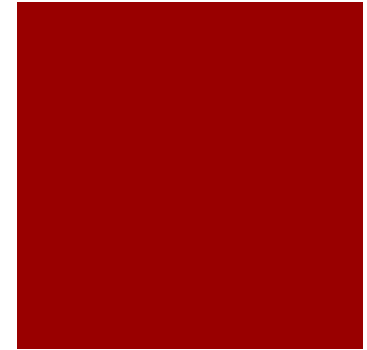
Estimated progression was faster in untreated than treated children: many of the former were enrolled earlier and died before having the chance to be treated.

HIV infected adolescents



- “Survivors”, and often live with other infected persons
- Many of them are orphans living with:
 - Grandparents or extended family
 - Adopted
 - Foster care

HIV infected adolescents



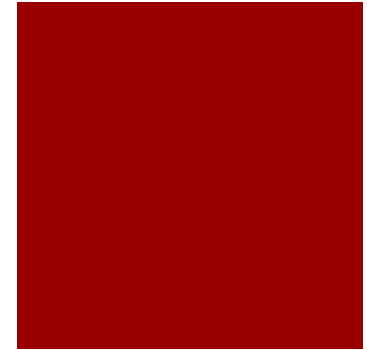
- HIV infection diagnosis should be early disclosed (by the age of 12)
- Gynecological follow-up for girls
- Emotional support
- Counseling on adherence
- Counseling on alcohol, tobacco, cannabis and other drugs
- The transfer to adult care has to be prepared

HIV infected adolescents



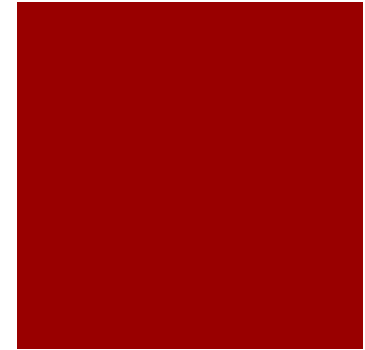
- Regular medical checkups plus...
 - Dentist
 - Nutritionist
 - Dermatologist
 - Psychologist/psychiatrist
 - Social worker
- Academic attainments and professional opportunities
- Peer meetings (with other HIV-infected adolescents)

HIV infected adolescents



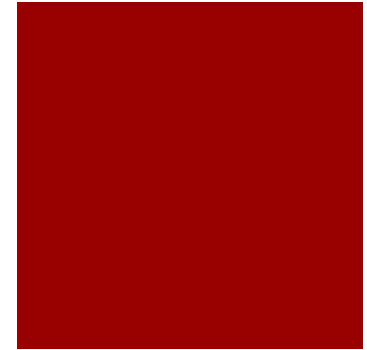
- Increasing difficulties with HAART at this age:
 - Changes in PK/PD characteristics
 - Adherence difficulties (meals, weekends...): **main cause of HAART failure**
 - Advanced disease
 - Resistance-associated mutations accumulation → low number of ART drugs available
 - Interactions with other drugs
- Always choose the “easiest” regimen
- Inform the patient about the drugs, involve him/her the treatment choice and get his/her commitment

Why is HIV Disclosure Important?



- May increase a child's willingness to adhere to treatment regimen
- Helps children understand the illness
- Avoids an accidental disclosure from occurring (e.g., child overhears caregiver discussing it)
- May decrease behavior problems by decreasing stress
- May improve social functioning and school performance by decreasing stress

Timing of Disclosure



Will depend on:

- Caregiver's acknowledgment of disease and readiness to disclose
- Child's cognitive skills and emotional maturity (including ability to maintain confidentiality)

Disclosure process should not be rushed, but timing of disclosure becomes more pressing as child nears adolescence.

Strategies to Facilitate Caregiver Readiness to Disclose HIV Diagnosis to Their Children

Caregiver Fear	Strategy to Overcome
Child is too young or emotionally immature to understand disclosure issues	Partial disclosure: Tell child that medications help keep him/her as healthy as possible. Then, as part of disclosure plan, more information is given, little by little, as the child matures. Introduce the idea of an immune system, or a part of the body that fights infections.

Caregiver Fear	Strategy to Overcome
Child will not understand when not to disclose	• Assess child's cognitive and emotional ability to understand and maintain confidentiality and discuss assessment with caregiver • Offer to create a "contract" that outlines who the child can tell and who the child cannot tell.
Child's reaction will be very difficult	• Assure the caregiver that the team will provide support for the family and child before, during, and after disclosure, including mental health assessment and treatment if necessary.

Caregiver Fear	Strategy to Overcome
Biological parent feels guilty for transmitting HIV infection	• Counsel to help alleviate guilt • Engage parent in an affirming and helpful role with child to promote empowerment • Refer for mental health treatment if necessary.
Caregiver is worried about questions that child may ask about caregiver's sexual behaviors or drug use	• Use role playing to prepare caregivers to answer embarrassing or painful questions • Help caregiver decide how to answer questions that may be asked

Reason for Reluctance	Strategy to Overcome
Caregivers disagree about disclosing to child	Assess each person's concerns and work together to develop a plan. Provide mental health/social work support if necessary
Foster parent and foster agency disagree about disclosure	Arrange for discussion among foster parents, foster agency, and clinical team

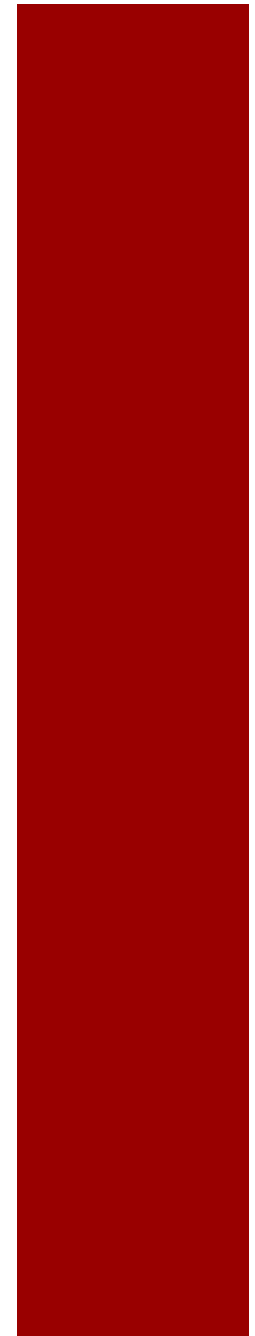
Factors to consider when developing an individualized disclosure Plan

- **Lying is NOT an option**
- Child's age, cognitive ability, and developmental understanding of illness and mortality
- What child has already been told and what child already knows about medications or doctor visits
- Clinical status of child
- Other disclosures that may need to be made (e.g., adoptive status, paternity issues, or parental HIV diagnosis)

Factors to consider when developing an individualized disclosure Plan

- Caregivers' thoughts about disclosure
- Cultural influences
- Family/social circumstances
- Anticipated response of child when learning diagnosis
- Effect on HIV-infected and non-infected siblings
- Types of support available to the child and family once disclosure occurs (e.g., counseling, peer support groups)

Preparing the
HIV-infected
adolescent for
the transfer to
adult care



Hallmarks of Adolescent Development



- Sense of immortality
- Risk taking is the norm
- Emerging sense of identity, autonomy and independence
- Challenging authority figures
- Experimentation with sex and gradual development of sexual identity
- Experimentation with substance use
- Peer pressure, positive peer relationships
- Focus on body image

Adolescence is a time of transition



- Changes in context that may increase risk:
 - Leaving school
 - Leaving home
 - Entering first serious relationship (increase in sexual contact/frequency/partners)
 - First pregnancy
- Context of adolescent sex that may affect risk:
 - Episodic sex that is less likely to be protected
 - Limited access to prevention and knowledge– lack experience/self-confidence/skills

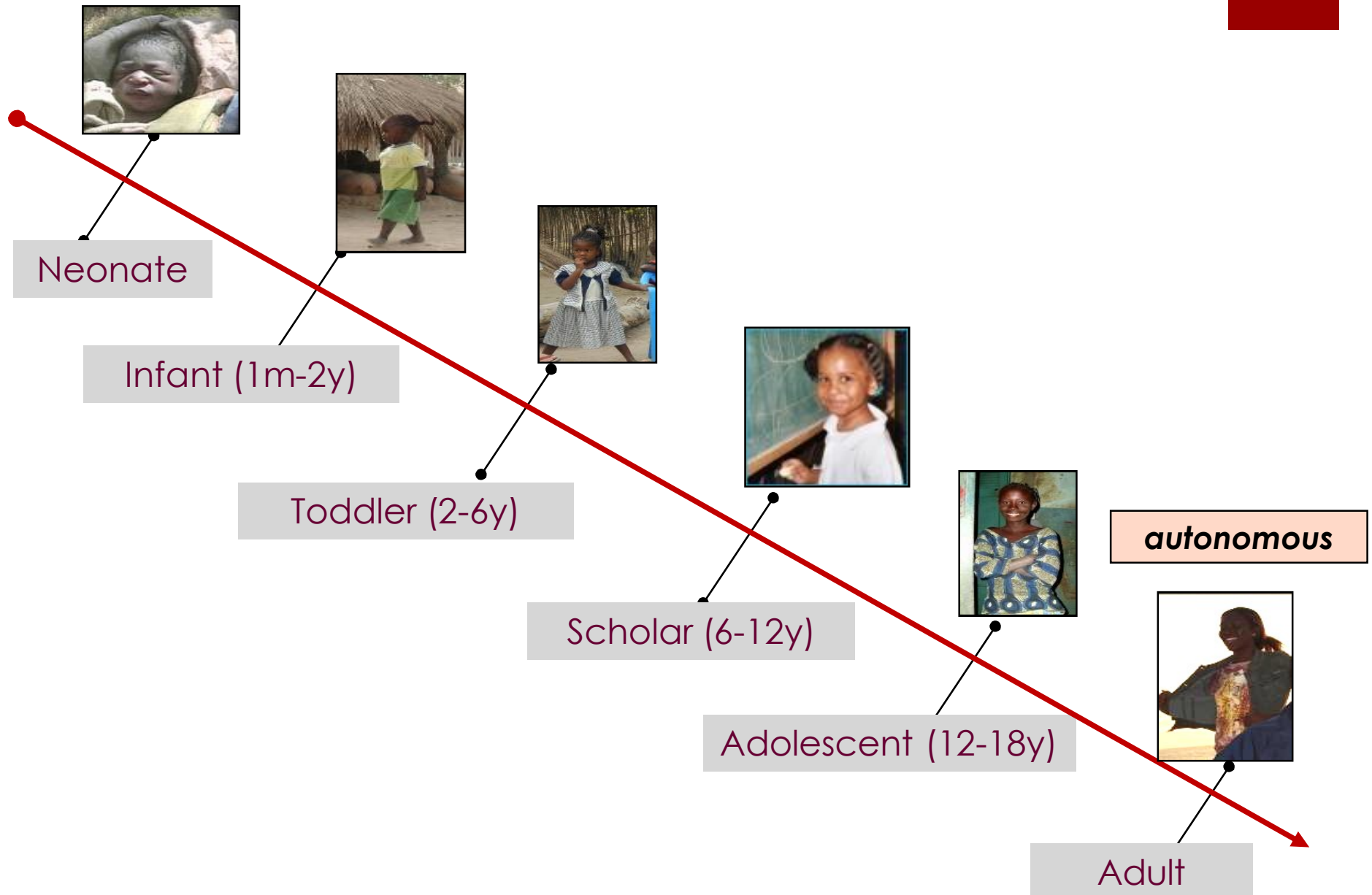
Mental Health and Psychosocial Issues



- With chronic illness, transition to young adulthood is characterized by psychological distress.
- Many teens with HIV deal with
 - Deaths of parent (s), siblings, friends
 - Lack of family support, community, teachers, schools, society
 - Anger/fear/depression about diagnosis
 - Poverty, substance abuse, violence, trauma, abuse, neglect

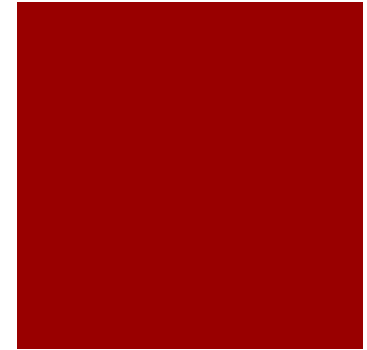
dependent

Somatic, emotional and social evolution



Teen Perspective

Autonomy and Independence



- *“Why do you have to tell my mom everything?”*
- *“No one trusts me!”*
- *“I’m not taking another pill until you tell me what’s wrong with me!”*
- *“Why didn’t anyone tell me my diagnosis sooner? Didn’t anyone think I can handle it?”*

Provider and Family Perspective

Autonomy and Independence



- Nurturing versus pampering
- Balancing between giving teen autonomy and risking his/her getting sick
- Fearing loss or limitations in control, lack of power
- Using another provider for “the sex talk” in long-term provider-child relationships

Interventions

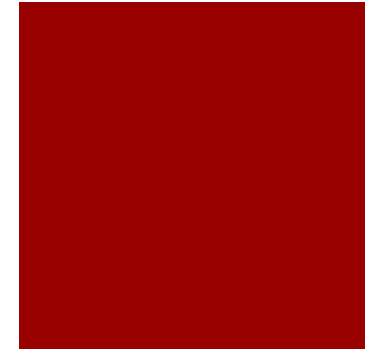
Autonomy Versus Dependence



- Help developing life skills
 - Daily living and basic needs
 - School and work
- Self-care skills
 - Healthy living and managing HIV
 - Medication Management and Adherence
- Counseling parents about power struggles

Interventions

Managing Their Own Care



- **Information:** What do they know and need to know?
- Adherence to treatment and care
 - Where is the teen in continuum of managing medications?
 - Teen's health beliefs and attitudes
 - Evaluate behavioral, environmental and emotional factors influencing adherence
- Empowering the teen
 - What are your expectations?
 - Taking charge of their healthcare
 - Change their sense of entitlement—"You have to **earn** this"
 - Consider short-term vs. long-term care plan

Body Image



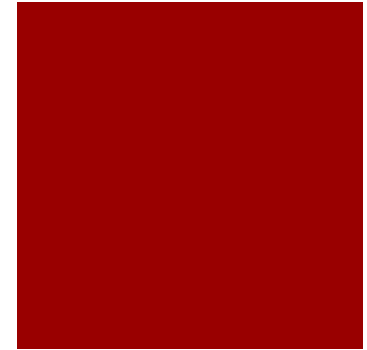
- Adolescence is a time to define oneself; body image is in the forefront.

“Am I developing normally?”

“Do I look OK?”

“Am I sexually attractive?”

HIV and Body Image



- Growth and development
- Lipodystrophy
- Wasting
- Obesity
- Skin conditions
- Medical appliances (*i.e.* gastrostomy)

Interventions & Strategies

Body Image



- Address growth or pubertal delays
- Consider a proposed treatment's effect on body image and lifestyle
- Involve teen in decisions
- Be willing to change treatment plan

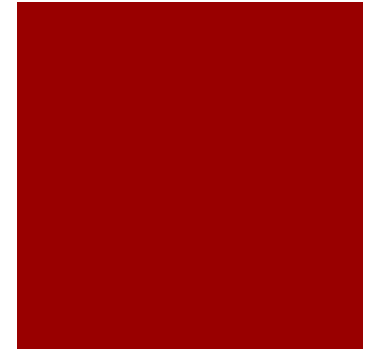
Peer Relationships

- The focus of adolescent relationships shifts from family to peers, and the peer group sets behavior standards.

“Yeah I have a tattoo—
all my girlfriends have one.”

- Fearing rejection, disclosure to peers is rare— only to a best friend after “testing” relationship, e.g.,
“How do you feel about people with AIDS?”

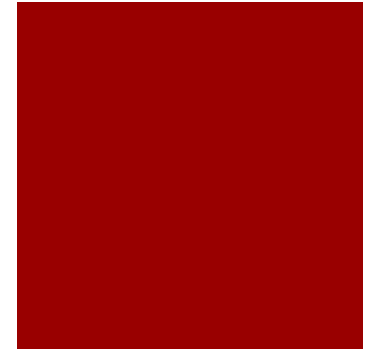
School



- May be behind in grade, have cognitive delays or special learning needs
- Absenteeism may be an issue
- Disclosure to the school is rare
- Education and/or vocational training are important in the long-term

Youth Sexual Behaviors

General Population



- 46% ever had sexual intercourse
- 14% ever had four or more sex partners
- 42% did not use a condom during last sexual intercourse
- 82% did not use birth control pills during last sexual intercourse
- 89% had received HIV/AIDS education

Teen Perspective

Sexuality



- Anxiety regarding
 - Sexuality
 - Sexual relationships
 - Reproductive and sexual functions
- *“I have the same doctor since I was a baby; he’s like my parent. I can’t talk to him about sex. I don’t want to disappoint him.”*
- *“I’m going to yes them to death because I can’t tell them the truth.”*

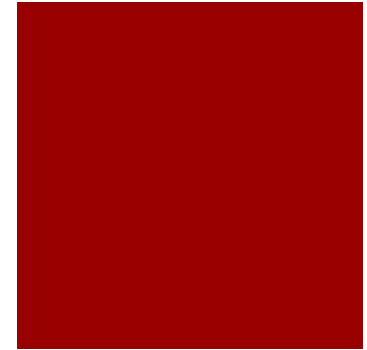
Provider Responsibility

Anticipatory Guidance



- Discuss sexual anatomy and function, and contraception
- Teach basics regarding transmission; discuss safe and responsible sex
- Encourage caregivers to recognize need for teen sexual identity
- Have videos, pamphlets, youth magazines in the clinic/office

Reproductive Health/ Family Planning



- Many adolescents, HIV-infected or uninfected, want to have children
- Can be a strong desire; they have personal sense of mortality

“I want to leave some part of me on the earth”

- Assure teens that they **can** have children safely when the time is right

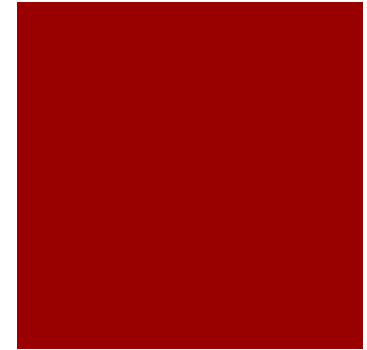
HIV and Plans for the Future

- Planning for the future is hard for teens
 - They were not expected to survive into adulthood
 - Their future *remains* uncertain
 - Many experience depression, loss, hopelessness and despair
- Career Planning Support
 - To develop skills for job and independence
 - Key—stay well to be part of the future

“I’m older now— I actually have to do something with my life.”

Interventions

School to Work



- Start early—build expectations
- Identify passion and skills for future job
- Encourage education as much as possible
- Find mentors
- Teach or refer for life skills
- Assist teen in taking care of their own entitlements

Transfer to adult
care



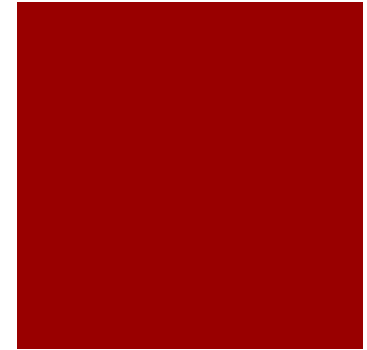
Principles of Healthcare Transition



- Begin healthcare transition early
- Continuity of care is the goal
- Transition planning should be comprehensive
- Involve teen and family
- Service coordination, communication and collaboration between providers is essential

Interventions & Strategies

Transition



- Maintain a relationship with teen and family
- Stimulate discussion about teen's future
- Understand the nature and implications of teen's chronic illness
- Determine time for transition discussions based on teen's development and needs
- Practice family-centered care
- Include support groups, mental health consultation and family planning component

Challenges to successful transitioning



- Adolescents and/or family and/or care team resistant to change.
- Radical differences in expectations and clinic cultures between pediatric/adult care settings.
- Communication difficulties between providers.
- Inadequate time and resources in adult medicine practice settings.

Challenges to successful transitioning



- Stigma of being infected with HIV and, for many-HIV youth, the additional stigma being gay, transgender, a substance user, or a teenage mother.
- High rates of teen pregnancy
- Non-disclosure to partners or roommates.
- Non disclosure by parent or guardian
- Recognize different needs of perinatally infected vs behaviorally infected youth

Transition Resources

Practitioner Transition Checklist & Timeline

Healthcare	Age 14–16	Age 17–19	Age 20–24
Meet privately with youth for part of visit	✓✓	✓✓	✓✓
Encourage youth to assume increasing responsibility of own health care	✓✓	✓✓	✓✓
Education			
Focus on youth's course of study as it relates to their long-term plans and goals	✓✓	✓✓	✓✓
Employment			
Initiate discussion of different routes to employment, e.g. higher ed or technical training	✓✓	✓✓	✓✓

Youth-friendly HIV care



- Providers who are knowledgeable, nonjudgmental
- Confidentiality and Consent
- Socioeconomic: poverty, work, school, housing & transportation challenges
- Empowering youth to LIVE with HIV
- Integrated care/"one stop shop"

Prevention with Positives



- Key element of HIV care and public health
 - Importance of age-appropriate messaging
- Prevention messages
 - Protect yourself/others from STIs and new HIV
 - Condomize every time you have sex
 - Engage partners: testing/disclosure if safe
 - Fewer partners = less risk
 - Drugs and alcohol = greater risk (SEP)
 - Consider not having sex (other ways to express love)
 - Discuss safe pregnancy options (PMTCT)

Summary: successful transitioning

Paediatric-adolescent team:

- Diagnostic disclosure
- Follow-up:
 - Clinical/immune
 - HAART / adherence
 - Prevention
- Transfer to adult care to begin early
- Future planning
- Coordination with adult team

Adult team:

- Know special characteristics of perinatally infected youth
- Adapt daily practice to those characteristics:

A propos of a case #1

Joana is a 16-year-old HIV-infected girl on Atripla. She is coming with her boyfriend, who knows nothing about her HIV infection, because of 8-wk amenorrhea.

- Pregnancy test is positive
- Ultrasound confirms gestation

What to do?

- Regarding gestation
- Disclosure of gestation to her parents
- Disclosure of HIV to her boyfriend

A propos of a case #2



- Pere is a 14-year-old perinatally-HIV-infected boy. He is currently doing well, with normal CD4 counts, but 2 last viral loads have showed blips despite of HAART: viral failure.

Why is he failing?

- Low adherence; he knows he is infected but ignores HIV.
- Low adherence; change in daily habits.
- Low adherence; drug user?

A propos of a case #3

- A previously healthy 17-year-old boy is coming with his mother because of a rash. He wants her mother to leave the room and admits having had risky homosexual relationships. He wants us to test him for HIV.
- HIV and syphilis test positive
- **What to do regarding disclosure to parents**

References:

- <http://www.cdc.gov/topics/surveillance/resources/slides/adolescents.indez.htm>
- <http://www.medscape.com/viewarticle/7748356>
- <http://www.AdolescentAIDS.org>
- <http://www.hivcareforyouth.org>

Moltes gràcies

cfortuny@hsjdbcn.org

ton@hsjdbcn.org