

*Emerging Concerns in the
Treatment of Adolescents:*

*Transitioning Youth from
Pediatrics into Adult Care*

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Disclosures

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Has no financial interest or relationships to disclose.

Defining Transition

It is a process of adjustment, as part of normal, healthy development, which is meant to meet individual needs as they proceed from childhood to adulthood, with the goals of maximizing lifelong functioning and potential and increasing and maintaining independent behavior.

AAP, AAFP, ACP-ASIM -- 2002

Consensus Statement on Health Care Transition

Pediatric Chronic-Illness Care Models

Two Groups of HIV-Infected Youth

- Perinatally-infected
- Behaviorally-infected
- These two groups have both distinct and shared clinical and psychosocial characteristics

Who is an Adolescent?

- AAP: 12-21 years old
- SAM: 10-24 years old
- APA: 10-18 years old
- AMA: 11-21 years old
- WHO: 10-19 years old

In general, the second decade of life, is the time between “childhood” and “adulthood.”

TRANSITIONING YOUTH INTO ADULT CARE

Principles of Transitioning

- Process vs. event
- Begins the day of diagnosis
- Provider reminders to *let go*
- Adolescent must be involved in the decision-making
- Coordination across the SYSTEMS is essential

Perinatally HIV-Infected Youth: Clinical Issues

- **growing size of this cohort**
- **more likely to have depressed immune function and require HAART**
- **more likely to be at advanced stages of HIV disease**
- **more likely to have history of previous OI's with complications and deficits**
- **more likely to have multi-drug resistance**
- **greater obstacles to achieving functional autonomy due to physical and developmental deficits**
- **higher mortality rates**

Perinatally HIV-Infected Youth: Clinical Issues

- Metabolic complications
 - Abnormal fat accumulation & wasting
 - Abnormal lipid profiles
 - Insulin resistance
 - Osteopenia/bone disease
- Mitochondrial toxicity
- Liver disease
- Renal disease
- Adolescent obesity

Behaviorally HIV-Infected Youth: Clinical Issues

- **more likely to be “healthy”**
- **more likely to be in earlier stages of HIV disease**
- **less likely to require HAART/ no resistance to ARV medications**
- **more likely to receive simpler HAART regimens when needed**
- **more likely to achieve functional autonomy**
- **have long-term chronic disease outlook**

HIV Care Models: Pediatrics

- **family-centered, comprehensive, coordinated systems of care**
- **longstanding relationship with care givers**
- **primary care integrated into HIV specialty care**
- **youth's rights for confidentiality and consent**
- **need for specialty consultants (i.e. gynecologist)**

HIV Care Models: Adolescent Medicine

- **teen-centered in discreet, teen-friendly intimate setting**
- **maybe minimal to no relationship with parent/care-giver**
- **primary care approach integrated into HIV care**
- **“core” teen health care services (sexuality, pelvic examinations/Pap smears, STI screening & tx, reproductive health, substance use, prevention education, adherence approaches)**

HIV Care Models: Adult

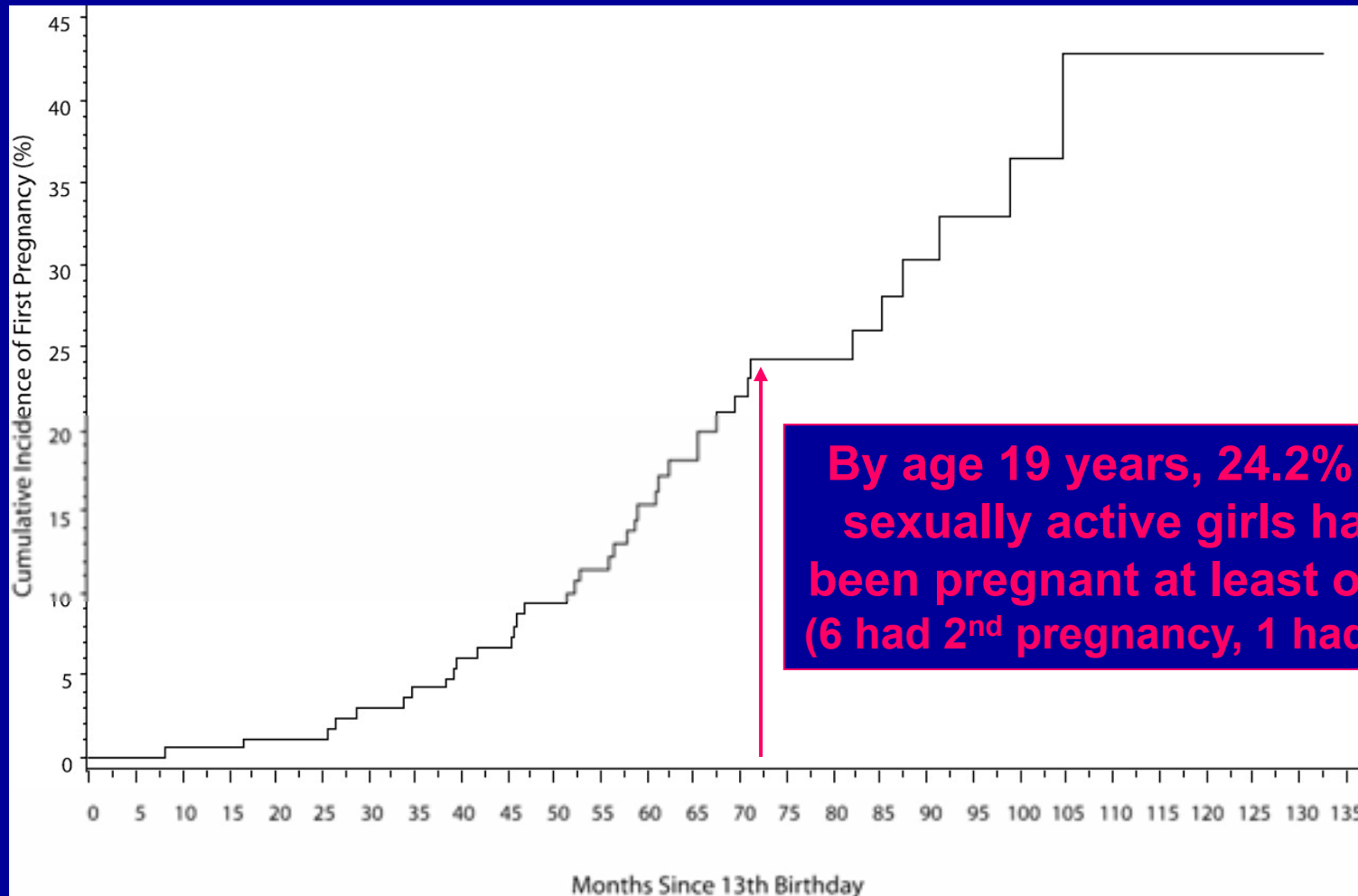
- **strict medical model (very short visit)**
- **adult medical providers more often
Family or Internal Medicine vs. ID
specialists**
- **expectations to behave as ‘adults’**
- **provider unfamiliar with transitional
issues**
- **transitioned patients may “slip
through the cracks” unless very
motivated**

Issues of Concern

- ❖ Self-disclosure
- ❖ *HIV knowledge*
- ❖ Identity
- ❖ Self-respect
- ❖ Physical growth
- ❖ Sexual development
- ❖ Taking responsibility
- ❖ *Negotiation skills*
- ❖ Decision making
- ❖ *Health choices and participation*
- ❖ Experimentation
- ❖ Sexuality
- ❖ *Reproductive health*
- ❖ *Cognitive abilities*

Cumulative Incidence of First Pregnancy in 174 Perinatally HIV-Infected Sexually Active Girls Age >13 Years, PACTG 219C

Brogly SB et al. Am J Public Health 2007;97:1047-1052



By age 19 years, 24.2% of sexually active girls had been pregnant at least once (6 had 2nd pregnancy, 1 had 3rd)

Barriers to “Successful” Transition

- Mental health
- Substance use
- **‘AIDS’** clinic/physician:
 - Lack of anonymity
 - Complex adult clinic system vs. familiar pediatric clinic
 - Very ill patients
- Lack of knowledge regarding adult clinic models of care and procedures

Facilitators of Transition

- Patient maturity
- Patient independence
- Strong support system
- Matching patient to adult provider/clinic
 - Sexual orientation
 - Access – location, transportation

Facilitators of Transition: Adult Provider

- Tour prospective clinical/private practice sites
- Interaction between pediatric and adult settings:
 - Adult provider included in an adolescent clinic visit
 - Peds/AM team member accompanies patient to first adult provider appointment (or not?)
 - Adult provider splits time between Peds/AM and Adult clinic

Facilitators of Transition

- Education/support groups
(life skills & health promotion workshops)
 - Knowledge: meds, labs
 - Skills: how to get prescriptions filled, arrange transportation, schedule appointments
 - Self-advocacy

Facilitators of Transition

- Youth mentors/buddies
- Youth becoming expert in their own health care
- Providing in-service training for adult healthcare providers
- Nurse or social worker overseeing transition process

Models for Psychosocial Support

- Have social worker continue to follow client for first year (formal/informal)
- Continue with same case management services
- Involve peer advocate
- Understand that process is fluid and dynamic

Where to Begin...

- Have a clinical infrastructure in place
- Develop a program transition protocol
- Identify appropriate adult care providers who are comfortable with the age group developmentally and familiar with chronic diseases of youth
- Consider patient-specific issues

...how to continue

- Include youth in transition policy development
- Formulate and implement screening tools
- Develop “Life Skills” curriculum
- “Graduate” class

Life - Skills

- 10 week program
- Didactic (multiple lessons)
- Holistic approach
- Designed for HIV positive youth to normalize illness
- Promotes growth, empowerment and success
- 8–15 participants
- Educational & fun
- Curriculum developed partly by the youth, based on their interests and needs
- Designed to teach concepts in an easy way in a safe environment
- Curriculum changes according to youth needs
- Teen survival guide

Life - Skills

- One – on –one intervention
- Four-hour intensives
- Breakfast & lunch
- Gift card (incentive)
- Pre/Post test evaluation

Life – Skills Topics

- Anger Management
- Communication Skills
- Writing Skills Workshop
- Getting the Right Job
- Handling Stress
- Navigating Health Care System
- Keeping Healthy
- Building Job Interviewing Skills and Resumes
- Our Money: How Can We Make It Last
- Sexual Health and Reproduction
- Street Drugs: What They Do To Us
- I'm So Blue...What to Do

Transition Evaluation

How can the number of youth *successfully* transitioned be accurately determined?

- Tracking systems:
 - HIPAA issues
 - Lack of IT connection b/t youth and adult sites
 - Is there funding for this?
- Define “success”:
 - engaging/retention in care?
 - taking meds?
 - attending first appointments?

Transition Evaluation

- Focus groups: pediatric and adult providers, pre-transition and post-transition patients, caregivers
- Satisfaction surveys (provider, setting, support services)
- Funded endeavor

Lessons Learned

- Need for ongoing evaluation!
- Self-esteem and confidence issues remain
- **HUGE** knowledge gap among youth regarding transition process

Transition Goals

- Youth become valuable members of society (civic participation)
- Finish high-school...improve higher education outcomes
- Become gainfully employed
- Develop and engage in healthy relationships
- Live well independently

Take Home Tips

- **Have a structured plan in place**
- **Discuss transition early**
- **Offer options**
- **Work with “appropriate” adult providers**
- **BE FLEXIBLE!**

Take Home Tips

- Google it!
- Read the literature....



Enjoy the Journey