

Transitional Care for HIV and AIDS from Adolescence to Adulthood

Jeffrey M. Birnbaum, MD, MPH

**Asst. Professor of Pediatrics, SUNY
Downstate Medical Center**

**Program Director, HEAT and FACES
Programs, SUNY Downstate Medical Center**

“Transition is a multifaceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Health care transition facilitates transition in other areas of life as well (eg. work, community, and school).”

-Reiss, J, Gibson R. Health Care Transition: Destinations Unknown. *Pediatrics*. 2002;110:1307-1314

“Most developmental transitions create anxiety... timing of the transition will depend on developmental readiness, complexity of the health problems, characteristics of the adolescent and family, and the availability of skilled adult health providers.

Transition is more complex and generally more difficult for those with more severe functional limitations or more complicated medical conditions.”

-Reiss, J, Gibson R. Health Care Transition: Destinations Unknown. *Pediatrics*. 2002;110:1307-1314

Increasing Average Age of Survival for Childhood Chronic Diseases

-Cystic Fibrosis:

1973 7 years

2002 21 years or greater

-Spina Bifida:

1970's <33% reached 20 years

2002 >80% reached 20 years

-Sickle Cell Disease/Renal Disease:

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-Reiss, J, Gibson R. Health Care Transition: Destinations Unknown.
Pediatrics. 2002;110:1307-1314

Hallmarks of Adolescent Development

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

Hallmarks of Adult Development

-Independence:

Self-reliant, independency, move from family home to independent living

-Establishing personal identity:

**Sense of who I am as unique individual
Critical aspect of achieving sense of independence**

-Establishing intimacy:

Young adults desire intimate relationships, sharing experiences with another

Multiple Transitions

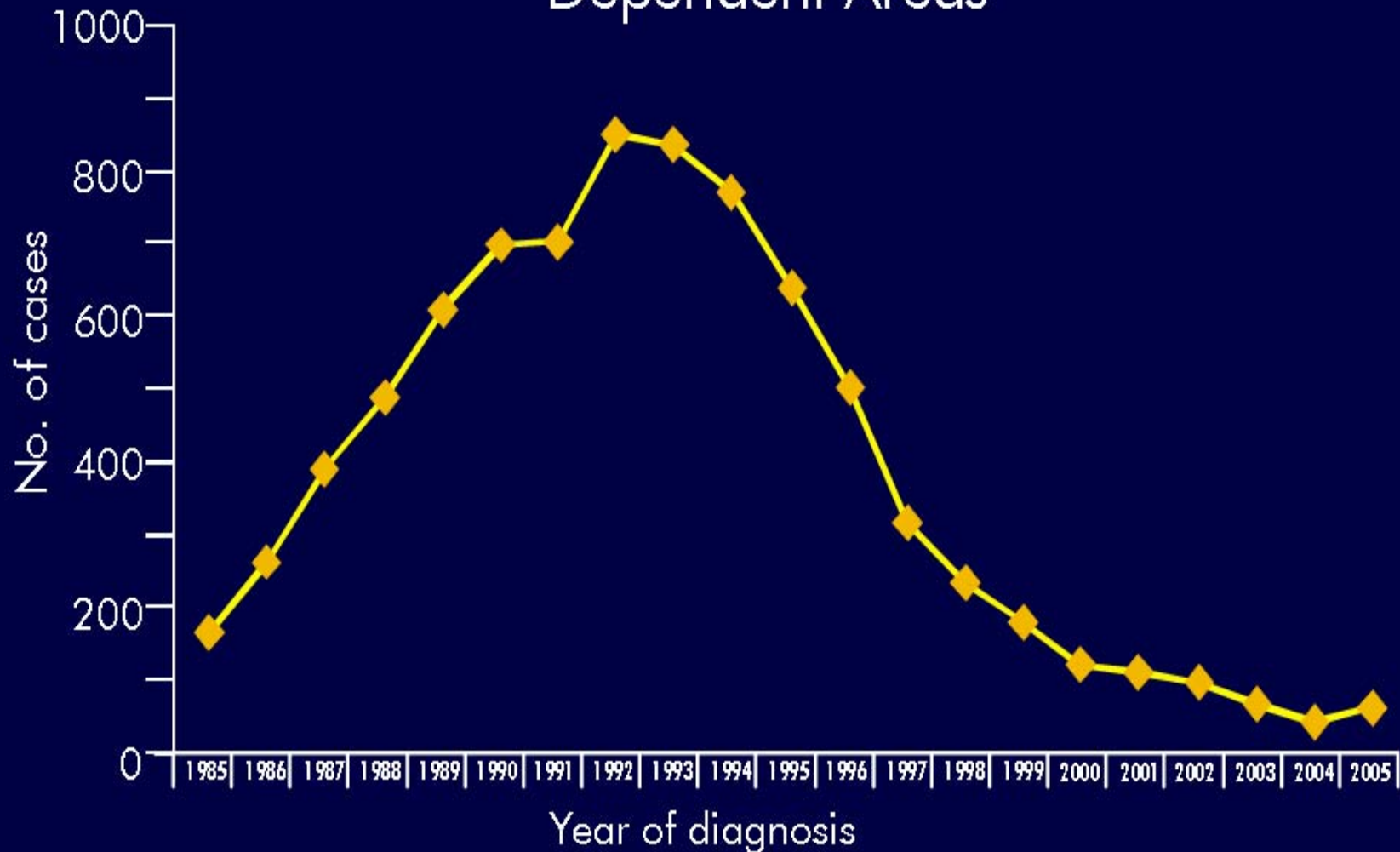
- multiple simultaneous transitions
- doctor, clinic setting, self consent for care
- foster care
- school
- camps and youth programs
- cumulative loss and bereavement
- “where do I fit in?”

Two Epidemiologic Subgroups

- **Perinatally Infected with HIV**
- **Behaviorally Infected with HIV**

- **These two groups have both distinct as well as shared clinical and psychosocial characteristics**

Estimated Number of Perinatally Acquired AIDS Cases by Year of Diagnosis, 1985–2005—United States Dependent Areas



Note: Data adjusted for reporting delays and cases without risk factor information were proportionally redistributed.
Presented at the NY HIV Research Centers Consortium 2007 Scientific Conference - "Living with HIV: Challenges for Interdisciplinary Research"



Reported AIDS Cases in Children <13 Years of Age by Transmission Category, 2005 and Cumulative United States and Dependent Areas

<u>Transmission Category</u>	<u>2005</u>		<u>Cumulative</u>	
	<u>Number</u>	<u>%</u>	<u>Number</u>	<u>%</u>
Perinatally acquired	86	92	8,637	91
Transfusion-associated	0	0	386	4
Hemophilia	0	0	230	2
Other/not reported	7	8	188	2
<u>Total</u>	<u>93</u>	<u>100</u>	<u>9,441</u>	<u>100</u>



Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

Perinatal:

- more likely to be in more advanced stages of HIV disease and immunosuppression
- more likely to have hx of OI's with complications/disabilities (eg. blindness, O₂ dependent, chronic renal failure)
- more likely to have heavy ARV exposure hx therefore more likely to have multi-drug resistant virus
- more likely to require HAART to control viremia, low CD4 counts

Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

Perinatal (cont.):

- more complicated ARV regimens (eg. “mega-HAART”)
- more complicated non-ARV medications such as OI prophylaxis/treatment
- greater obstacles to achieving functional autonomy due to physical and developmental disabilities/greater dependency on family (eg. “adult” vulnerable child)
- when pregnant, higher risk of complications during more advanced stages of disease and of second generation HIV transmission due to multiple-drug resistance

Mental Health Profile of Perinatally Infected Adolescents

“....although a high prevalence of behavioral problems does exist among HIV-infected children, neither HIV infection nor prenatal drug exposure is the underlying cause. Rather, other biological and environmental factors are likely contributors toward poor behavioral outcomes.”

Mellins, Smith, et al.

WITS Study, Pediatrics. 2003 Feb, 111(2):384-93

Mental Health Profile of Perinatally Infected Adolescents

- Forty-seven perinatally-infected youths 9-16 years of age and their primary caregivers recruited from a pediatric HIV clinic were interviewed using standardized assessments of youth psychiatric disorders and emotional and behavioral functioning, as well as measures of health and caregiver mental health.
- According to either the caregiver or child report, 55% of youths met criteria for a psychiatric disorder. The most prevalent diagnoses were anxiety disorders (40%), attention deficit hyperactivity disorders (21%), conduct disorders (13%), and oppositional defiant disorders (11%).

Psychiatric disorders in youth with perinatally acquired human immunodeficiency virus infection.

Mellins et al. *Pediatr Infect Dis J.* 2006 May;25(5):432-7

Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

Behavioral:

- more likely to be in earlier stages of HIV disease
- less OI complications
- no previous ARV exposure
- less likely to be resistant to ARV's
- less likely to require HAART
- when HAART required can give simpler regimens
- treatment adherence problems may be relatively simpler to manage than perinatal group
- more likely to achieve functional autonomy

Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

Pediatric:

- family-centered and multidisciplinary care with pediatric expertise
- medical provider has more long standing relationship with care giver at home
- primary care approach integrated into HIV care
- issues of HIV disclosure to patient and youth's confidentiality/right to consent
- care usually offered in discreet, child-friendly and intimate setting
- teen services supplemental to existing services

Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

Adolescent:

- teen-centered and multidisciplinary care; provider may have minimal to no relationship with parent/care giver
- primary care approach integrated into HIV care
- youth often does not disclose HIV status to family
- issues of confidentiality and consent; care usually offered in discreet, teen-friendly and intimate setting
- teen services core to clinic-sexuality, pelvic examinations/Pap smears, STD screening and tx, reproductive health, substance use, rights to confidentiality and consent, treatment education and adherence approaches

Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

Adult:

- adult-oriented care based on strict medical model
- Adult medical providers more often ID specialists than are pediatric or adolescent providers
- young person's transitional issues usually not given any systematic specialized focus
- clinics tend to be very large and easy for transitioning patients to "slip through the cracks" unless very motivated

Barriers to Successful Transitioning

- **Provider resistance from both sides of the “bridge” and communication difficulties between pediatric/adolescent and adult providers; “cultural” differences in provider settings**
- **adolescent and/or family resistance to change, lack of knowledge about health care transition**
- **HIV-specific barriers to transitioning-role of disclosure of HIV status, stigma, simultaneous transition of medical, mental health and case management providers**

What Are The Research Questions That Need To Be Addressed?

- What definitions and models for transitioning work best?
- How do youth who transition access services in adult care? Do they access a variety of services in adult care or just medical care?
- Does their experience in the peds/adol setting affect how or whether they access a variety of services in the adult setting?

What Are The Research Questions That Need To Be Addressed?

- Descriptive analysis of those who successfully transition (cross-sectional analysis). What do they look like?
- What factors are associated with successful transition? Eg. 4 appt's" in the adult program in one year concept as a measure
- What factors are associated with unsuccessful transition? Eg. How do you conduct research on a cohort not in care?

What Are The Research Questions That Need To Be Addressed?

- What else can we measure besides transition of care? Eg. Life skills, patient satisfaction in adult care
- How do you measure life skills?

Life Skills That an Adolescent Needs for Successful Transition to an Adult Clinic

- Knowing when to seek medical care for symptoms or emergencies
- Being able to identify one's symptoms and describe them
- Using one's primary care provider appropriately
- Making, canceling, and rescheduling appointments
- Coming to appointments on time
- Calling ahead of time for urgent visits
- Requesting prescription refills correctly and allowing enough time for them to be refilled before needed
- Negotiating multiple providers and subspecialty visits
- Understanding the importance of healthcare insurance and how to get it
- Understanding entitlements and knowing where to go for each
- Establishing a solid relationship with a new case manager is also an essential skill for the adolescent

What Are The Research Questions That Need To Be Addressed?

- Comparison of perinatally infected youth vs. behaviorally infected youth in transitioning
- Are their differences in life skills between perinatally infected vs. behaviorally infected?
- What early interventions (Young Achievers Group-pre-teen) might be associated with better outcomes?
- Does teen pregnancy and motherhood enhance or deter transition?
- What mental health factors or does early engagement in MH have an impact on transitioning?
- Can we develop a collaborative network of sites to research these questions? Eg. FACES Network vs. consortium of NY sites