Transitional Care for HIV and AIDS from Adolescence to Adulthood

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Featured Speaker

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Conflict of Interest Statement

The speakers and their viewpoints represent no conflicts of interest.

Evaluations

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Learning Objectives

At the end of this broadcast, the learner will be able to:

- Define transitional care for HIV/AIDS
- List some of the key hallmarks of adolescent development and how they affect adolescents living with HIV
- Describe data trends among perinatally-infected adolescents
- Describe clinical differences and similarities between perinatally-infected and behaviorally infected adolescents living with HIV
- Describe psychosocial differences and similarities between perinatally-infected and behaviorally infected adolescents living with HIV
- List ways in which HIV clinical care for youth differs from adult care
- Describe barriers to successfully transitioning from pediatric to adult HIV care

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Background Concepts

- Age group: 18-24 years
- Definition of “transition”
- Developmental Concepts

Background Concepts

- Two subgroups:
  1. Perinatally infected with HIV:
     - First generation of long term survivors
  2. Behaviorally infected with HIV
- Unique clinical issues within each group
- Different Models of Care
- Case Studies
- Outcomes in transition

“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).”

“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.”


### Increasing Average Age of Survival for Childhood Chronic Diseases

<table>
<thead>
<tr>
<th>Condition</th>
<th>Year</th>
<th>Average Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic Fibrosis</td>
<td>1973</td>
<td>7 years</td>
</tr>
<tr>
<td></td>
<td>2002</td>
<td>21 years or greater</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Condition</th>
<th>Year</th>
<th>Average Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spina Bifida</td>
<td>1970’s</td>
<td>&lt;33% reached 20 years</td>
</tr>
<tr>
<td></td>
<td>2002</td>
<td>&gt;80% reached 20 years</td>
</tr>
</tbody>
</table>


### Hallmarks of Adolescent Development

- Sense of immortality
- Risk taking is the norm
- Emerging sense:
  - Identity
  - Autonomy
  - Independence
- Challenging authority figures

### Hallmarks of Adolescent Development

- 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
  - Independence
  - Move from family home to independent living

Establishing personal identity:
- Sense of self as a unique individual
- Critical aspect of achieving sense of independence

Establishing intimacy:
- Young adults desire:
  - Intimate relationships
  - Sharing experiences with one another

Simultaneous transitions including:
- Doctor, clinic setting, self-consent for care
- Foster care
- School
- Camps and youth programs

Transitions result in:
- Cumulative loss and bereavement
- "Where do I fit in?"

Two Epidemiologic Subgroups

- Perinatally infected with HIV
- Behaviorally infected with HIV

Two groups have:
- Distinct clinical and psychosocial characteristics
- Shared clinical and psychosocial characteristics

Timeline

- 1982 - First reports of perinatal transmission of HIV in New York, New Jersey and California
- 1996 - Release of first protease inhibitors leading to trend of increased survival
- 2004 - 20 approved antiretroviral agents
  - 5 different classes
  - Several combination pills
  - Regimens with lower pill counts
  - Once a day regimens
Trends in Long Term Survival from Perinatal HIV Infection

- In 2006: 42% of adolescents living with HIV/AIDS in NYS infected with HIV before age 13
- This proportion will likely decrease over time.
- Very few infants currently are born with perinatal HIV infection (approximately 10 in NYS in 2009).
- Majority of perinatally HIV-infected are older adolescents who require transitioning from adolescent to adult health care services and providers.

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

Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

Perinatally infected population is more likely to:
- be in more advanced stages of HIV disease and immunosuppression
- have history of OI’s with complications or disabilities
- have heavy ARV exposure history
- have multi-drug resistant virus
- require HAART to control viremia, low CD4 counts

Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

Perinatally infected population is more likely to: (cont.):
- Need more complicated ARV regimens (e.g. “mega-HAART”)
- Need more complicated non-ARV medications such as OI prophylaxis/treatment
- Face greater obstacles to achieving functional autonomy due to physical and developmental disabilities/greater dependency on family (eg. “adult” vulnerable child)
- Face higher risk of complications during more advanced stages of disease and of second generation HIV transmission due to multiple-drug resistance when pregnant
Mental Health Profile of Perinatally Infected Adolescents

Rates of categories of psychiatric disorder by caregiver or youth report among 206 HIV+ perinatally infected youth:
- Any psychiatric disorder 60.7%*
- Anxiety disorder 49.0%
- Mood disorder 7.3%
- Behavioral disorder 25.7%
- ADHD 18.0%*
- Substance Abuse 1.9%

*Statistically significant compared to perinatally HIV- exposed comparison group

Mental Health Profile of Behaviorally Infected Adolescents
(self-reported)

- Hx of depression (non-HIV related) 55.7%
- Hx of suicidal ideation 20%
- Hx of suicidal gestures/attempts 30%
- Hx of other psychiatric dx 24.3%
- Dropped out of JHS, HS or college 32.4%

Mental Health Profile of Behaviorally Infected Adolescents (self-reported)

- Substance use:
  - EtOH 23.6%
  - Marijuana only 3.64%
  - EtOH/Marijuana 38.2%
  - Crack/Cocaine 20%
  - IVDU 1.82%
  - Other 16.4%

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

“Supplemental” Clinical Services for Perinatally Infected Youth

- Sexuality
- Pelvic examinations/Pap smears
- STD screening
- Pregnancy
- Substance use
- Issues of treatment options
- Treatment adherence

Youth Rights to Consent and Confidentiality in New York State

- STD screening and treatment
- Family planning/birth control
- Prenatal care
- Termination of pregnancy
- HIV counseling and testing
- HIV care
- Substance abuse treatment
- Mental health services
- Transgender care
Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

**Adolescent:**
- teen-centered and multidisciplinary
- provider may have minimal 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

**Adolescent:**
- Care usually offered in setting that is:
  - Discreet
  - Teen-friendly
  - Intimate

**Adult care:**
- Based on strict medical model
- More often provided by ID specialists than pediatric or adolescent providers
- Does not specialize in transitional issues
- Provided in large clinics with danger of transitioning patients to “slip through the cracks” unless very motivated

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

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

- Requesting prescription refills correctly
- Allowing enough time for refill
- 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
Barriers to Successful Transitioning

- Provider resistance from both sides of the “bridge”
- 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?

- Comparison of perinately infected youth vs. behaviorally infected youth in transitioning
- Are there differences in life skills between perinately infected vs. behaviorally infected?
- What early interventions (eg. pre-teen or early adolescent groups) 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?

Recommendations

- Orient patients and families towards the future emphasizing long term survival
- Develop a transition plan early when it is still many years ahead
- Foster personal and medical independence early;
  - children should assume some responsibility for their treatment at home and at school;
  - adolescents should permitted and encouraged to participate in decision-making and consent

Recommendations

- Transition plans should be multifaceted and individualized:
  - Medical: old provider should be familiar with new provider as clinician and the environment in which they provide care
  - Mental health: goal should be to transition psychotherapy/psychiatric services simultaneously with medical services; often a challenge
  - Psycosocial: housing/entitlements, health insurance should all be in place
  - Life skills: educational goals, job training, parenting, etc.

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