TRANSITIONING HIV-INFECTED YOUTH TO ADULT SERVICES

Ana Garcia, PhD, LCSW
Assistant Professor of Clinical Pediatrics
Ryan White Part D Pediatric Coordinator
Miami Family Care Program
University of Miami Miller School of Medicine
Division of Pediatric Infectious Diseases & Immunology
Who is an Adolescent?

- American Academy of Pediatrics: 12-21 years old
- Society of Adolescent Medicine: 10-24 years old
- American Psychological Association: 10-18 years old
- American Medical Association: 11-21 years old
- World Health Organization: 10-19 years old
Adolescents

- Not children, not adults
- Some are childlike in thought and behavior
- Maybe physically are adult-like
- Have ongoing brain and cognitive changes
2011 AAP Statement on Transition

* Health care transition planning starts at age 12
* Actual transition planning at age 14
* Age 16-17: transition planning well established
* Age 18: initiate adult model of care, even if no transfer of care
* Written transition policy should be prominently displayed
* Each practice should use a standard transition plan
* Review transition plans regularly and update
* Complete medical records delivered to adult provider, as well as portable health summary to youth/family
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 function and potential, and increasing and maintaining independent behavior.
Principles of Transitioning

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

**Disease-specific**

- Pediatric specialist to pediatric/adult specialist (Med-Peds?) to adult provider (IDT follows across the spectrum)

**Generic**

- Patient moves from pediatrics (birth-14) to adolescent (15-24) to adult (>24 years)
## MODELS OF TRANSITION SERVICES

### Primary Care
- Primary Care Provider (PCP) is care coordinator
- Specialist is the consultant

### Single Site
- Pediatric to adolescent - to adult care within the same environment
- Clinical services remain constant
UM Transitioned Youth Population

Infectious Diseases & Immunology

- Oldest patient is 36 y/o
- 122 youth ages 21 – 24 have transitioned since 2003
- 97 (80%) have selected care outside of UM/JMH
- 17 (14%) expired shortly after transition
Transitioning:
The Youths’ Perspective
ASK QUESTIONS!

- when does transition begin for me?
- who will help me with this process?
- what do I need to know?
Interdisciplinary Team

- Physicians
- ARNPs
- Nurses
- Social workers
- Psychologists
- Dietitian
- Research staff
- Peer educators & advocates
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
Issues Impacting Care

- Substance abuse
- Educational needs
- Mental health
- Housing
- Transportation
- Financial assistance
- Legal/juvenile justice involvement
Transition Challenges for Adolescents with Perinatally-Acquired HIV

- Secrecy vs. public disclosure
- Traumatic losses (parents, siblings, extended family)
- Complications of chronic illness and ARV meds
- Multiple drug resistance
- Problems with adherence (pill fatigue)
- Evolving sexual awareness, sexual identity
- Pregnancy and childbearing
- HIV secondary prevention and legal concerns
LIFE-SKILLS TOPICS

- Anger Management
- Communication Skills
- Writing Skills Workshop
- Getting the Right Job
- Handling Stress
- Navigating Health Care Systems
- Keeping Healthy
- Building Job Interviewing Skills and Resumes
- Our Money: How Can We Make It Last
- Dress for Success
- Street Drugs: What They Do To Us
- I’m So Blue…What to Do
Transition Challenges: Provider and Patients

- Lack of time for transition
- Young adult patients prefer pediatric centers
- Adult centers are found to be cold, hostile, and overly efficient
- Communication barriers exist between young adult patients and health providers
- Lack of funding for transition programs
- Lack of understanding of illness by adult providers
Number of medical visits declines after transfer to adult care

Patients self-report low adherence to treatment after transfer

Difficulty in establishing rapport with adult provider

Lack of appointment reminders

Perception that adult providers don’t value them
Where to Begin...(providers)

- Develop a program transition protocol
- Identify appropriate adult care providers who are comfortable with the developmental age group and familiar with chronic diseases of youth
- Consider patient-specific issues
...how to continue

- Establish client focus groups
- Include youth in transition policy development
- Formulate and implement screening tools
- Develop a “Life Skills” curriculum
TRANSITIONING YOUTH INTO ADULT CARE

SUCCESSFUL STRATEGIES

- Pediatric provider recommends adult provider options
- Pediatric provider offers youth medical history
- Mentors/Buddies
- Youth becoming expert in their own health care condition
- Multiple intervention strategies (support groups, newsletters)
- Providing in-service training for adult healthcare providers
- Nurse or social worker coordinating transition process
Transition: LESSONS LEARNED

- Need for ongoing evaluation
- Esteem and confidence issues remain
- Decrease in medical appointment adherence due to atmosphere and style of engagement found in adult clinic settings
- Knowledge gap among youth regarding transition
- Uncertainty about insurance eligibility, financial concerns, and service policy’s
SUMMARY

Need to celebrate transition successes

• Normalize transition as an expected part of the developmental and care process

• Anticipatory guidance with regards to culture of adult care centers

• Keep in mind long-term survival and quality of adult life
Donald is an HIV-perinatally-infected young man who transitioned out of Pediatrics 2/15/16, on his 24th birthday.

- FSIQ = 49
- small statured and his physical appearance resembles that of a 12 y/o
- struggled with adherence to his ARTs since age 18, when his guardian (he is an orphan) no longer supervised his care
- last VL was 497,897 and his CD4 has been <20 (0%) for the past six years
- he lives alone and has a poor support system
- Sexually active
- Multiple hospitalizations –last visit asked to be tested for HIV
Thank you.....questions?
• Additional Questions?

• AGarcia2@med.miami.edu
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The information presented is the consensus of HIV/AIDS specialists within the SEAETC and does not necessarily represent the official views of HRSA/HAB.

The AIDS Education and Training Center (AETC) Program is the training arm of the Ryan White HIV/AIDS Program. The AETC Program is a national network of leading HIV experts who provide locally based, tailored education, clinical consultation and technical assistance to healthcare professionals and healthcare organizations to integrate high quality, comprehensive care for those living with or affected by HIV.
The **South FL SE AIDS Education and Training Center** within the University of Miami, Department of Medicine, Division of Clinical Immunology, has over thirty faculty members and staff dedicated to caring for patients with HIV/AIDS and includes some of the world’s most renowned researchers in infectious diseases. We have specialty clinics in adult medicine, and obstetrics/gynecology that provide state of the art clinical care for those individuals infected with HIV and other STIs. HIV clinical care is provided by the UM physicians for inpatient care at Jackson Memorial Hospital (JMH) and University of Miami Hospital, and outpatient care at numerous sites on the UM/JMH medical campus. UM HIV faculty also provide off site care at Federally Qualified Health Centers.
The South FL SE AETC includes the following counties: Polk, Hardee, Highlands, Indian River, Okeechobee, St. Lucie, Hernando, Pasco, Pinellas, Hillsborough, Manatee, Sarasota, DeSoto, Martin, Palm Beach, Broward, Miami-Dade, Monroe, Charlotte, Glades, Lee, Hendry and Collier.
The U.S. Department of Health and Human Services (DHHS) has released updated versions of its antiretroviral treatment guidelines for adults and adolescents, and for children with HIV. The new adult guidelines include revised recommendations for first-line antiretroviral therapy (ART) as well as management of treatment-experienced patients. The revised pediatric guidelines include a discussion of very early treatment for HIV-infected infants.

References
HHS Panel on Antiretroviral Guidelines for Adults and Adolescents. *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. Updated April 8, 2015.

TRAINING OPPORTUNITIES

Preceptorships
An intensive clinical training program offered to healthcare providers in Florida who have an interest in learning more about the diagnosis and management of HIV/AIDS, opportunistic infections, and co-morbid conditions. Each preceptorship is structured to meet the unique needs of the individual participant based on his or her previous experience, geographic location, and time available. Experience 4 to 240 hours of clinical training at adult, pediatric, obstetric, and/or family practice clinics where care is provided to HIV-infected patients. All training provided is consistent with current guidelines from the Department of Health and Human Services or other nationally recognized guidelines when available.

Individual and/or Group Clinical Consultations
Individual and group clinical consultations are offered. Individual clinical case consultation is provided on the diagnosis, prevention, and treatment of HIV/AIDS and related conditions. These consultations take place by telephone, email or face-to-face meetings. Group clinical consultation with case-based discussions include information on pharmacology, clinical antiretroviral therapy updates, drug-drug interactions, and antiretroviral resistance.
TRAINING OPPORTUNITIES Cont’d

Chart Reviews
The chart review program offers clinics that provide HIV/AIDS care an opportunity to assess adherence to current Department of Health and Human Services (DHHS) and other published guidelines utilized in the care and treatment of HIV-infected individuals. Using a team of specially-trained F/C AETC faculty, a review of selected patient charts is completed to identify the strengths of the healthcare team, as well as areas of opportunity for education and training to support quality improvement efforts.

Web-Based Education (Webinars)
We offer numerous web-based educational opportunities to increase the knowledge and skills of HIV healthcare providers. Our web-based educational opportunities cover a wide range of HIV-related topics. Trainings are provided both as live webinars or on-demand recorded webinars. Web-based education offers participants a way to stay up-to-date on current topics.

Telehealth Case Based Group Consultations
This model uses a live audio-video-based platform (Adobe Connect) to provide educational experiences through the creation of a learning network comprised of clinicians serving HIV/AIDS patients, novice to expert throughout our region.
FOR MORE INFORMATION, PLEASE VISIT:

http://hivaidsinstitute.med.miami.edu/partners/se-aetc
National HIV/AIDS Clinicians’ Consultation Center
UCSF – San Francisco General Hospital

**Warmline**
National HIV/AIDS Telephone Consultation Service
*Consultation on all aspects of HIV testing and clinical care*
Monday - Friday
9 am - 8 pm EST
Voicemail 24 hours a day, 7 days a week

800.933.3413

**PEPline**
National Clinicians’ Post-Exposure Prophylaxis Hotline
*Recommendations on managing occupational exposures to HIV and hepatitis B & C*
9 am - 2 am EST, 7 days a week

888.448.4911

**Perinatal HIV Hotline**
National Perinatal HIV Consultation & Referral Service
*Advice on testing and care of HIV-infected pregnant women and their infants*
*Referral to HIV specialists and regional resources*
24 hours a day, 7 days a week

888.448.8765

**HRSA AIDS ETC Program & Community Based Programs, HIV/AIDS Bureau & Centers for Disease Control and Prevention (CDC)**
www.nccc.ucsf.edu
Upcoming Webinars

Thursday, JULY 21st
HIV/HCV/ART Case Based Telehealth
*Group Consultation – UM/NSU Faculty*

Wednesday, JULY 27th
ARV Resistance and Resistance Testing
*Elizabeth Sherman, PharmD, AAHIVP*

Thursday, AUGUST 4th
Gynecological Care for Women with HIV
*Nelly Diaz, MPH, ARNP*
Need Additional Information?

Contact the South FL SE AIDS Education and Training Center

Franklin Monjarrez, Program Manager: fbm20@med.miami.edu
Tivisay Gonzalez, Program Coordinator: tgonzalez1@med.miami.edu
Target audience: Physicians, physician assistants, nurses, pharmacists, social workers, mental health workers, nutritionist/dietitians.

The Suwannee River Area Health Education Center, Inc. is a Florida Board of Nursing, Dentistry, Pharmacy, Psychology, Respiratory Care, Occupational Therapy, Nursing Home Administration, Clinical Social Work, Marriage and Family Therapy and Mental Health Counseling and Florida Council of Dietetics and Nutrition approved provider of continuing education. CE Broker Provider ID #50-1922.

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Thank you!