



# 2008 Update: HIV Care for Youth

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# Objectives

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- Epidemiology & statistics
- Youth & HIV: Transmission
- Youth & HIV: Demographics and Legal issues
- Youth & HIV
  - Counseling & Testing
  - Care Challenges and Barriers
  - Transitioning
  - Treatment



# HIV/AIDS is NOT over for Youth

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- 50% of new HIV infection among youth 13-24
- 20,000 US infections annually
- 2/3 HIV+ youth are sexually infected (40-50% of young women)
- 3/4 HIV+ youth are from racial/ethnic minorities
- 1/3+ HIV+ youth untested (80% of gay youth unaware of status)
- Growing numbers of perinatally infected reaching adolescence



## “Aging Up” of Children with HIV

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- Decreased mortality, longer survival
- Fewer perinatally infected children
- Delayed diagnosis
- Shifts the curve to the right, with more perinatally infected children becoming 13 years of age or older



# HIV Transmission among Youth

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- Perinatal Infection

- Growing numbers of youth: ARVs are prolonging life

- Sexual Infection (highest mode of transmission)

- Many at-risk women unaware of risk
- Many YMSM don't identify with "gay" prevention
- Transgender youth avoid or don't get care
- STI, sexual/substance abuse, mental illness increases risk
- Children of HIV+ parents at increased risk

# CHARACTERISTICS OF HIV + YOUTH

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- Newly diagnosed
- Denial of HIV status
- Trading sex for shelter/monetary gain
- Living in shelter/transitional (friend to friend)
- Low literacy level
- No emotional support from family
- No regular health care
- No financial stability
- Poor social skills
- Poor relationships with authority
- Substance abuse/mental health issues

# CHARACTERISTICS OF HIV + YOUTH

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- Female HIV + Youth typically:
  - 20 years of age or less with 2 + children
  - History of sexual trauma – molestation/rape
  - Clinical levels of depression with no intervention
  - Poor relationships with opposite sex
    - Constantly seeking acceptance from men
    - Sex is means of emotional connection
  - Much older partners



## Legal issues in adolescent care

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- Texas Statutes: Family Code Chapter 32 -§ 32.003. CONSENT TO TREATMENT BY CHILD. (a) A child may consent to medical, dental, psychological, and surgical treatment for the child by a licensed physician or dentist



## Youth may consent for self if :

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- In active duty with the armed services of the United States of America;
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- Is 16 years of age or older and resides separate and apart from parent/guardian regardless of the duration of the residence; and managing the child's own financial affairs, regardless of the source of the income;
- Consents to the diagnosis and treatment of an infectious, contagious, or communicable disease that is required by law or a rule to be reported to the Texas Department of Health,
- is unmarried and pregnant and consents to hospital, medical, or surgical treatment, other than abortion, related to the pregnancy;



## Youth may consent for self if :

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- consents to examination and treatment for drug or chemical addiction, drug or chemical dependency, or any other condition directly related to drug or chemical use;
- is unmarried, is the parent of a child, and has actual custody of his or her child and consents to medical, dental, psychological, or surgical treatment for the child;
- or is serving a term of confinement in a facility operated by or under contract with the Texas Department of Criminal Justice, unless the treatment would constitute a prohibited practice under Section 164.052(a)(19), Occupations Code.



# Providing care to a minor

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- Consent by a child to medical, dental, psychological, and surgical treatment under this section is not subject to disaffirmance because of minority.
- Consent of the parents, managing conservator, or guardian of a child is not necessary in order to authorize hospital, medical, surgical, or dental care under this section.
- A licensed physician, dentist, or psychologist may, with or without the consent of a child who is a patient, advise the parents, managing conservator, or guardian of the child of the treatment given to or needed by the child.
- A physician, dentist, psychologist, hospital, or medical facility is not liable for the examination and treatment of a child under this section except for the provider's or the facility's own acts of negligence.
- A physician, dentist, psychologist, hospital, or medical facility may rely on the written statement of the child containing the grounds on which the child has capacity to consent to the child's medical treatment.



# Engaging Youth into Care

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- The best approach to care
  - Multidisciplinary model with youth-friendly mission
  - Work on establishing trust and interest in youth
- Medical services
  - Comprehensive including sexual health services
- Psychosocial services
  - Case management
  - Mental health & substance abuse services
  - Risk reduction & contraception counseling
  - Disclosure counseling & support



# Providing HIV Care for Youth

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- Integrate primary, basic gynecology and HIV care
- Co-locate or have easily accessible mental health services
- Be able to access youth substance abuse services
- Have someone who is main contact for youth i.e., case manager, nurse, peer, etc.



# Psychosocial Issues among Positive Youth

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- Depression and other mental health illnesses
- Cognitive issues, school problems
- Homelessness, housing issues
- Drugs and alcohol issues
- Problems with the law
- Childhood abuse issues, emotional, physical, sexual
- Reproductive issues
- Lack of future planning



# Mental Health and Psychosocial Issues

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



# BARRIERS TO CARE

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## ○ **Financial Barriers**

- Not aware of resources
- Cannot afford medical care
- Cannot afford child care
- Type of jobs held are insensitive to medical needs
- Believe they cannot receive care without parental consent

## ○ **Cultural Barriers**

- Cultural beliefs regarding medication/treatment
- Ethnic beliefs towards medical providers
- Non-Citizenship or immigration problems creates fear about receiving services
- Chaotic lifestyle of youth



# BARRIERS TO CARE

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## ○ **Social/Emotional Barriers**

- Denial of Diagnosis
- Depression
- Domestic Violence
- Mistrust
- Fear of medical condition
- Fear of Disclosure and rejection
- Lack of information

## ○ **Environmental and Physical Barriers**

- Too ill to attend visit
- Clinic Hours
- Wait time
- Transportation
- Childcare
- Perceived lack of sensitivity
- Clinics aimed at child/adult care



# Transitioning

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- “Purposeful, planned movement of adolescents and young adults with chronic illness/disability from child-centered to adult oriented systems—health, employment, independent living.”

*Patience White, MD*

Transition is a process, not an event.



# Transitioning:

## Youth aging into and out of adolescent care

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- Facilitate transition from supportive to independent and responsibilities from parent/provider to patient
- Promote growth, self-expression and personal decision making
- Choose adult clinic with multidisciplinary services
- Traumatic for youth to leave trusted providers
- Uncomfortable in the presence of adult patients
- Consider phased transition (case manager, GYN)



# Principles of Healthcare Transition

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



# Antiretroviral Therapy: When to Start

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- DHHS guidelines for adults appropriate for youth?
  - Thymic volume and function favors youth
  - Slower progression to AIDS than adults
  - Adherence with youth more difficult
- Pregnant HIV+ young women should get ARVs to prevent perinatal transmission regardless of CD4 count/viral load
- Be aware of resistance issues with perinatally infected and other heavily treated youth
- Controversy on when to start; if healthy consider delay until adherence chances improve



# Antiretroviral Therapy: Youth Issues

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- Check for pubertal development
  - Tanner stage I or II- use pediatric dosages
  - Tanner V- use adult dosages
  - During Tanner III and IV dose according to status of growth spurt: Pediatric dosing prior to growth spurt and adult dosing post-spurt, monitor closely.
- Resistance testing before therapy initiation
- Avoid efavirenz-based regimens with females who might be or become pregnant
- Once daily, non-refrigerated meds improve adherence

# HAART Options for Youth

	Agent	FDA Approval Age/Dosing availability	FDA Pregnancy Category				
			A	B	C	D	X
<b>NRTIs</b>	Didanosine (Videx, ddl)	No dosing established for EC		B			
	Tenofovir DF (Viread)	18 years and up		B			
	Abacavir (Ziagen, ABC)	3 months and up			C		
	Emtriva (FTC)	3 months and up			C		
	Lamivudine (EpiVir, 3TC)	3 months and up			C		
	Stavudine (Zerit, d4T)	5 weeks and up			C		
	Zalcitabine (HIVID, ddC)	n/a			C		
	Zidovudine (Retrovir, AZT)	Birth and up			C		
<b>NNRTIs</b>	Delavirdine (rescriptor)	18 years and up			C		
	Efavirenz (Sustiva)	3 years and up				D	
	Nevirapine (Viramune)	2 months and up			C		
<b>PIs</b>	Nelfinavir (Viracept)	2 years and up		B**			
	Ritonavir (Norvir)	1 month and up		B			
	Saquinavir (Invirase, Fortovase)	16 years and up		B			
	Atazanavir (Reyataz)	18 years and up/ no dosing		B			
	Amprenavir (Agenerase)/fos-Amprenavir (Lexiva)	18 years and up/ no dosing			C		
	Indinavir (Crixivan)	18 years and up			C		
	Darunavir (Prezista)	18 years and up/ no dosing		B			
	Tipranavir ( Aptivus)	18 years and up/ no dosing			C		
	Lopinavir + Ritonavir (Kaletra)	6 months and up			C		

\*\* New FDA warning against use in pregnancy

## HAART Options for Youth: New Classes and Combo Pills

	Agent	FDA Approval Age/Dosing availability	FDA Pregnancy Category				
			A	B	C	D	X
Entry inhibitors	Enfuvirtide (t20) Fuzeon	6 years and up		X			
	Maraviroc (Selzentry)	18 years and up/ no dosing		X			
Integrase inhibitors	Raltegravir (Isentress)	18 years and up/ no dosing			X		

- Combivir- 12 years and up
- Trizivir- Not indicated for <40kg
- Epzicom- No dosing established
- Truvada- 18 years and up
- Atripla- 18 years and up



# Once-Daily Dosing for Youth

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- Abacavir – possible, no data
- Didanosine – useful and reasonable
- Emtricitabine – possible, no data
- Lamivudine – possible, no data
- Stavudine – awaiting the formulation?
- Tenofovir – possible, awaiting formulation
- Amprenavir – unlikely formulation
- Fos-Amprenavir – possible, no data
- Atazanavir – possible, no data
- Lopinavir-r – less likely, possible, no data
- Efavirenz – useful and reasonable, watch re: teratogenicity



# Treatment Challenges

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- Adherence- Forgetting, Denial, Lack of planning, Number of pills, dosing requirements, confidentiality concerns, other priorities
- Strategizing therapy
- Encouraging clinical trial participation
- Using phenotypes to maximize potential options
- ?Discussing break in treatment when risk of losing last option is high
- Discussing end of life options



# Antiretroviral Therapy: Adherence Barriers

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- Developmental issues are key
  - Denial of need for treatment
  - Concrete and present-oriented thinking
  - Adverse events may seem intolerable
  - Meds rebellion as a form of independence
- Low self esteem, depression, hopelessness
- Mistrust providers & misinformation from peers
- Socioeconomic: chaotic lifestyles, insurance, housing & transportation challenges
- Lack of support / disclosure



# Keeping Youth in Care

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- Creating a youth friendly environment
  - Regular in-services for staff regarding youth issues
    - Research protocols
    - New adolescent friendly regimens
    - Sharing of youth resources
    - Development of adolescent appropriate staff
  - Consumers advocates/peers are also a great support to staff
- Youth involvement in every process
  - Focus groups
  - Involve them in program development
  - Employment opportunities



## Best Practices for Adolescent HIV Care

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- Multidisciplinary approach
- Flexible schedules
- Specified youth contact person
- Honest, open discussions
- Frequent follow up communication
- Addressing the youth's agenda first
- Recruit and retain staff that like to work with youth

# CONCLUSION

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- Working with youth can be challenging
- Do your homework – learn about the youth
- Provide hands on service delivery
- Flexibility is key
- Ask what they need – they will tell you