

Adolescent HIV Medicine and Research

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What makes the adolescent unique?

Adolescence

- Broken down into three stages:
 - Early Adolescence (11-14)
 - Mid Adolescence (15-17)
 - Late Adolescence (18-21)
- Each stage has unique biological and psychosocial features
- This is dynamic with individual variability

Adolescence

- **Early**
 - **Concrete thought dominant**
 - **Little perception of consequences**
 - **Preoccupied with changing body**
 - **Body going through significant physiologic and hormonal changes**
- **Mid**
 - **Abstract thought emerges and matures**
 - **Revert to concrete thinking in times of stress**
 - **“Paradox of mid-adolescence” often leads to risk-taking behavior**
 - **Major conflicts over control**
 - **Behavioral code defined by group-sense of self defined by your peer group**
 - **Gender role stereotypic behavior**
- **Late**
 - **Abstract thought firmly established**
 - **Emancipation from other groups complete**
 - **Stable relationships emerge**
 - **Narcissism retreats**

Adolescent Brain Development

- In adolescence, brain maturation continues in the fronto-parietal systems and in the superior temporal sulcus
- Overall increase in WM between ages 4 to 21
- Corpus callosum development continues through childhood and adolescence
- Significant microstructural changes in WM continue through adolescence and correspond to changes in cortical GM regions
 - » Paus T Science, 2005
 - » Lenroot R and J Giedd, 2006
 - » Giorgio A et al. Neuroimage, 2007

Sexual Identity

Stages of Homosexual Identity Formation

Troiden (1988)

- Sensitization
- Sexual Identity Confusion
- Sexual Identity Assumption
- Integration and Commitment

*Troiden, RR. Homosexual identity development. *J Adolesc Health*. 1988; 9:105-113

What is our experience with
recruitment/retention of adolescents in
HIV-related research?

AMHARN Network

Adolescent Medicine HIV/AIDS Research Network

REACH Project

Reaching for Excellence in Adolescent Care and Health

Basic Science Group

Virologist
Medicine

Immunologist
Psychologist

Mucosal Immunologist

STD/Adolescent

Behavioral

Epidemiologist

Clinical Science Group

15 Clinical Sites

RETENTION RATES

- **HIV + Females: 246/271 (91%)**
- **HIV - Females: 140/164 (85%)**
- **HIV + Males: 84/96 (88%)**
- **HIV - Males: 39/47 (83%)**

Recruitment and Retention in Research- the REACH Experience

- Data collected from 438 subjects (66% HIV-positive/34% HIV-negative)
- Of 13 items, the following were ranked highest for both recruitment/retention
 - Quality medical care
 - Caring staff
 - Health education
 - Privacy/confidentiality
 - Altruism
 - Least important: social activities, compensation, transportation, food/snacks
 - » Stanford et al. J Adol Health 2003;32

PACTG 381

- Observational cohort study of 120 youth initiating combination antiretroviral therapy
 - 69/120 (58%) subjects achieved viral suppression by weeks 16-24
 - Perfect adherence was the only predictor of viral suppression
 - 55/69 (80%) continued to maintain viral suppression to week 60
 - Thus, early adherence very important for short and long term virologic success with HAART
 - Flynn et al. *J Infect Dis.* Jul 15 2004;190(2):271-279.
 - Rudy et al. *AIDS Research and Hum Retro* 2006; 22.

Final Results:

- Of 120 subjects, only 41 (34%) stayed on study treatment
- 20 remained on study but off medications and 58 were lost to follow-up
- 24/41 were on their original HAART regimen
- 29/69 (42%) who originally had virologic success continued with virologic success to week 156.

» Flynn P, Rudy BJ, Lindsey J, et al. (2007). *AIDS Res Hum Retroviruses*, 22 (3): 213-221.

What factors may affect an adolescent's ability to enroll and stay engaged in research?

Post-traumatic Stress and Trauma History in Adolescents and Young Adults with HIV

- **Methods**

- Recruited 30 HIV-positive subjects 18-24 years of age
- Trauma history obtained via the Traumatic Events Inventory
- PTSD and PTSS assessed with the Post-traumatic Stress Disorder Checklist-Civilian Version

- » Radcliffe et al AIDS Patient Care and STD's 2007, 21.

Results:

- 83% AA, 70% male
- 67% MSM for the males
- 60% reported traumatic stress symptoms consistent with PTSD or PTSS
- In response to HIV diagnosis, 16.7% reported symptoms consistent with PTSS and 13.3% met criteria for PTSD
- For other events, 23.3% reported symptoms consistent with PTSS and 26.7% met criteria for PTSD
- 50% reported that their HIV diagnosis was NOT the most traumatic event in their life

» Radcliffe et al AIDS Patient Care and STD's 2007, 21.

Barriers to Recruitment/Retention of Adolescents in Research

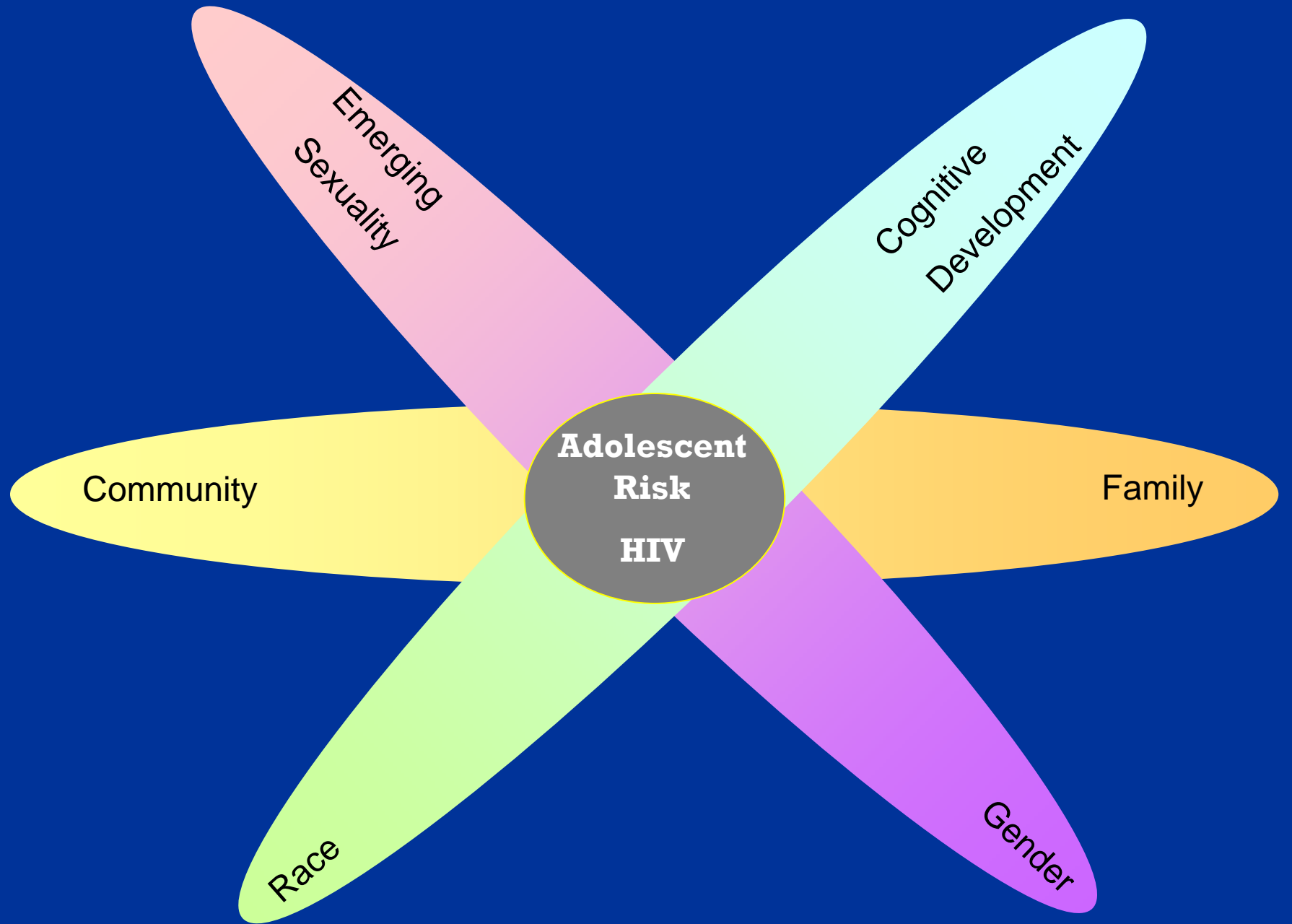
- Many at-risk adolescents face multiple barriers to participation in research including:
 - Poverty
 - Homelessness/functional homelessness
 - Substance use
 - Unstable social situations
 - Lack of social support
 - Co-morbidities such as mental health issues

Psychosocial Profile

- Understanding the needs of the patient is key to maintaining in research
- Done as part of comprehensive care supported by a multidisciplinary team including: social work/case management, mental health counselors, health educators, nurses, physicians
 - Areas covered
 - Basic needs- housing, child care, food, clothing, education, etc.
 - Mental health/substance abuse
 - Health insurance
 - Perceived health (other health concerns)
 - Legal issues
 - Support system
 - Disclosure- HIV status, sexual orientation
 - Special needs- language translation, hearing impairment, reading impairment, etc
 - Putting the new patient into a social context

Barriers for Clinicians/Providers

- Prioritizing research with other pressing clinical/social issues
 - STD's
 - Contraception
 - Violence
 - School issues
 - Legal issues
 - Other chronic medical conditions
- Time and skills to discuss/present research
- Personal issues for the providers
- Commitment to research
 - Non-research personnel presenting research to subjects
- The protective factor
 - “Parentification” of the providers
- Other funding obligations
 - Title X
 - CDC
 - HRSA



Prevention Research

- Complex in an adolescent/young adult population
 - Must be congruent with age/cognitive development
 - Must consider racial/gender/sexual identity/gender identity issues
 - Must be sustainable
 - Must involve the community
 - Prevention must be considered in a continuum:
 - Prevention
 - Identifying those infected
 - Linking those infected into care
 - Preventing secondary transmission