Adherence Issues in the Care of HIV-Infected Children & Adolescents

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The reality of HIV infection in children and adolescent in the Us

- Significantly reduced rates of mother-to- child transmission during pregnancy.
- Estimated 15,000 children & adolescent with perinatal infection are currently in the US
- Expected survival into adolescence & adulthood for those with perinatally acquired HIV infection.
- Growing number of adolescents with HIV infection due to risk-taking behaviors.

  (38,500+ with HIV diagnosis in US, ages 13-24).

HIV disease in children became a chronic illness

- HIV disease is treatable, yet not curable, requiring long-term management.
- Treatment is costly and difficult.
- As children live longer they are at greater risk of increased incidence and severity of complications, including mental health issues and psychiatric illness.

Why the increase in psychosocial morbidity in HIV-infected children?

- Unique challenges associated with HIV infection:
  - Neurological sequelae of HIV
  - Physical features
    - delayed growth
    - chronic organs conditions (e.g. Respiratory, cardiac, renal)
    - lipodystrophy

Why the increase in psychosocial morbidity in HIV-infected children?

- Unique challenges associated with HIV infection:

  Complicated medication regimens (frequency, palatability, pill burden)

  Noxious side effects of medications

Why the increase in psychosocial morbidity in HIV-infected children?

- Children with perinatally-acquired HIV often grow up in families with multi-generational exposure to:
  - poverty
  - family substance abuse
  - family mental health problems
  - family disruption
  - violence and trauma

Why the increase in psychosocial morbidity in HIV-infected children?

Stigma associated with HIV disease

Loss of significant family members/bereavement

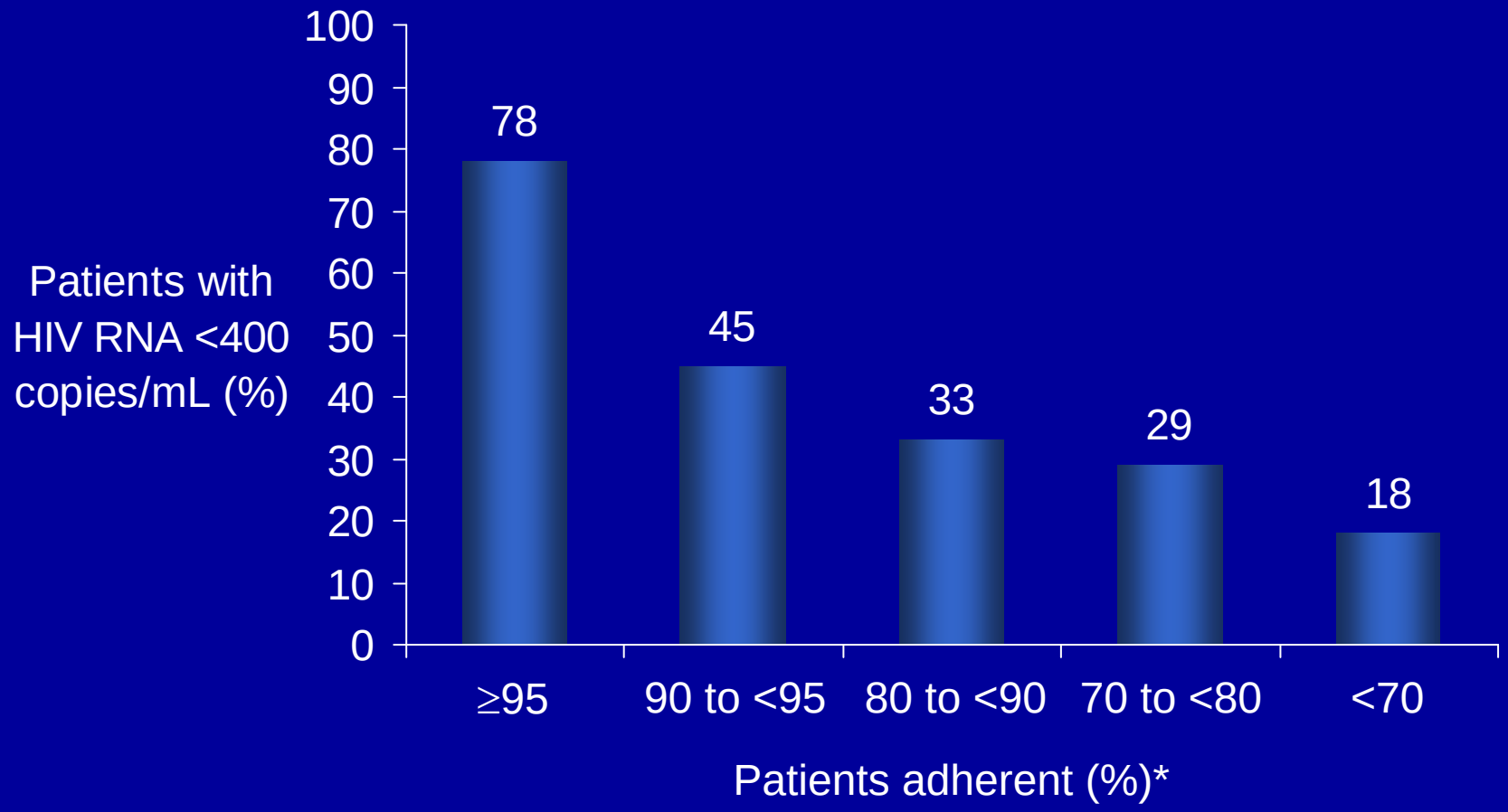
Disordered attachment relationships

Adherence Is Critical to Success of HIV Treatment

- Suboptimal adherence to ART regimens leads to
  - Incomplete viral suppression
  - Emergence of resistant virus
  - Compromise future therapeutic options
  - Regimen failure
  - Increased risk of mortality

Paterson DL et al. *Ann Intern Med*. 2000;133:21-30.

Medication Adherence: A Major Challenge in HIV Infection



*MEMS® cap data.

Paterson DL et al. *Ann Intern Med*. 2000;133:21-30..

From Medscape CME,GJ Treisman (with permission)

Barriers to Adherence in Children

Medication Regimen

- *Palatability of medication*
- *Formulation of medication*
- *Schedule*
- *Cost*
- *Toxicity*

Child factors

Caregiver factors

Health care professionals factors

lack of experience

Ineffective communication style

PACTG 219c Cohort of HIV-infected children & adolescents (n=2088)

- **Age Groups:**
  - **3-6** **186 (9%)**
  - **6-9** **387 (19%)**
  - **9-12** **564 (27%)**
  - **12-15** **556 (27%)**
  - **15-18** **395 (19%)**
- **48% Male, 52% Female**
- **59% Black, 25% Latino,16% Caucasian**
- **CDC Class C diagnosis: 27%**
- **56% take 6 or more doses per day of medication**

Williams et al, 2006

Health and Medication Characteristics of the Cohort

Neurological/developmental or psychiatric diagnosis-. 27% (n=560)

ADHD/Behavioral Disorders-11% (n=227)

Depression/Anxiety/Other Mood Disorders-3% (N=56)

Neurological/Developmental Diagnoses

Encephalopathy/CP- 11% (n=205)

Mental Retardation6% (n=128)

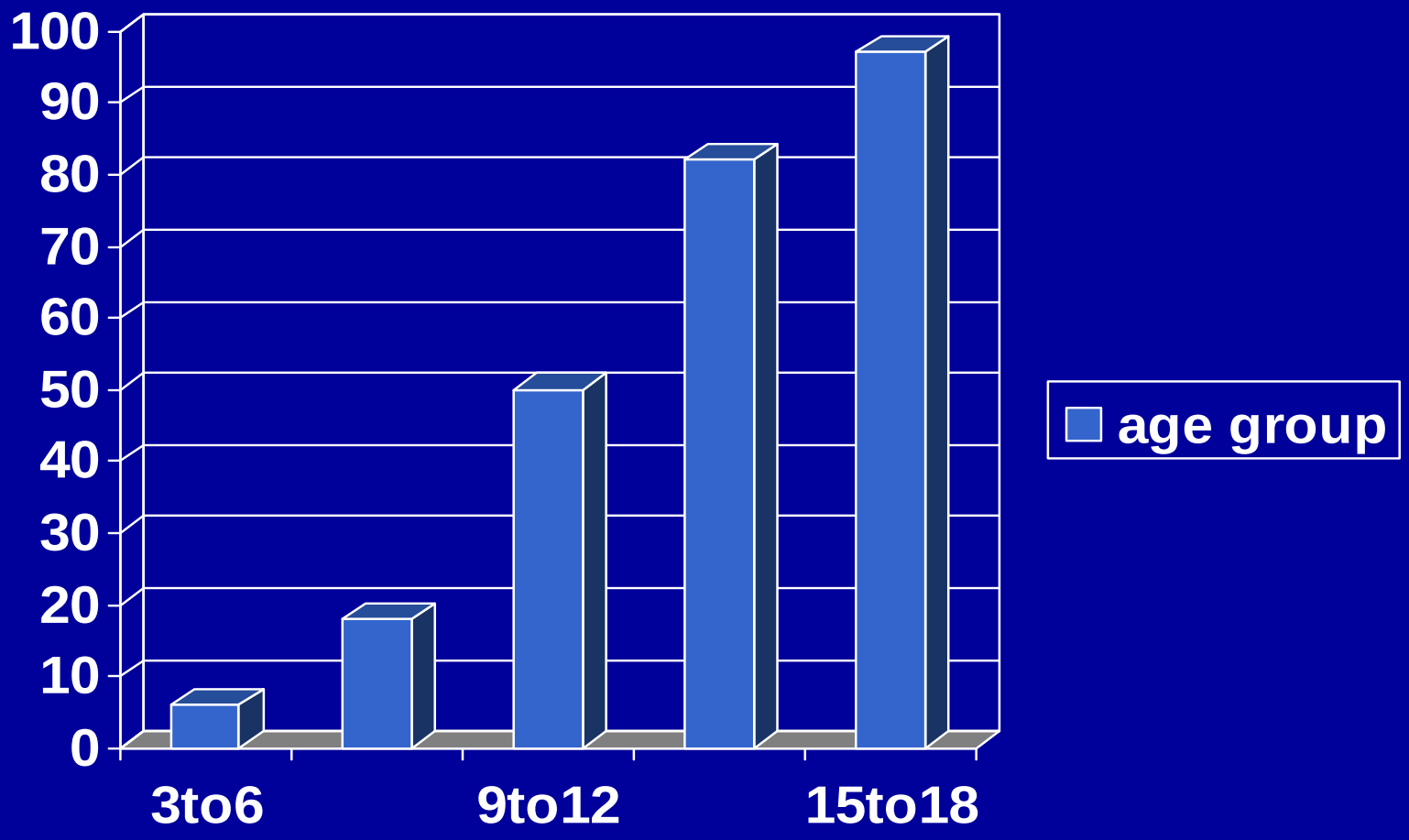
Epilepsy-4% (n=87)

15% of cohort receive medication for these diagnoses. (n=308)

Psychosocial Characteristics

- 46% with recent stressful life event
- 34% receive special education
- 26% repeated a grade in school

Percent with Knowledge of HIV Status By Age

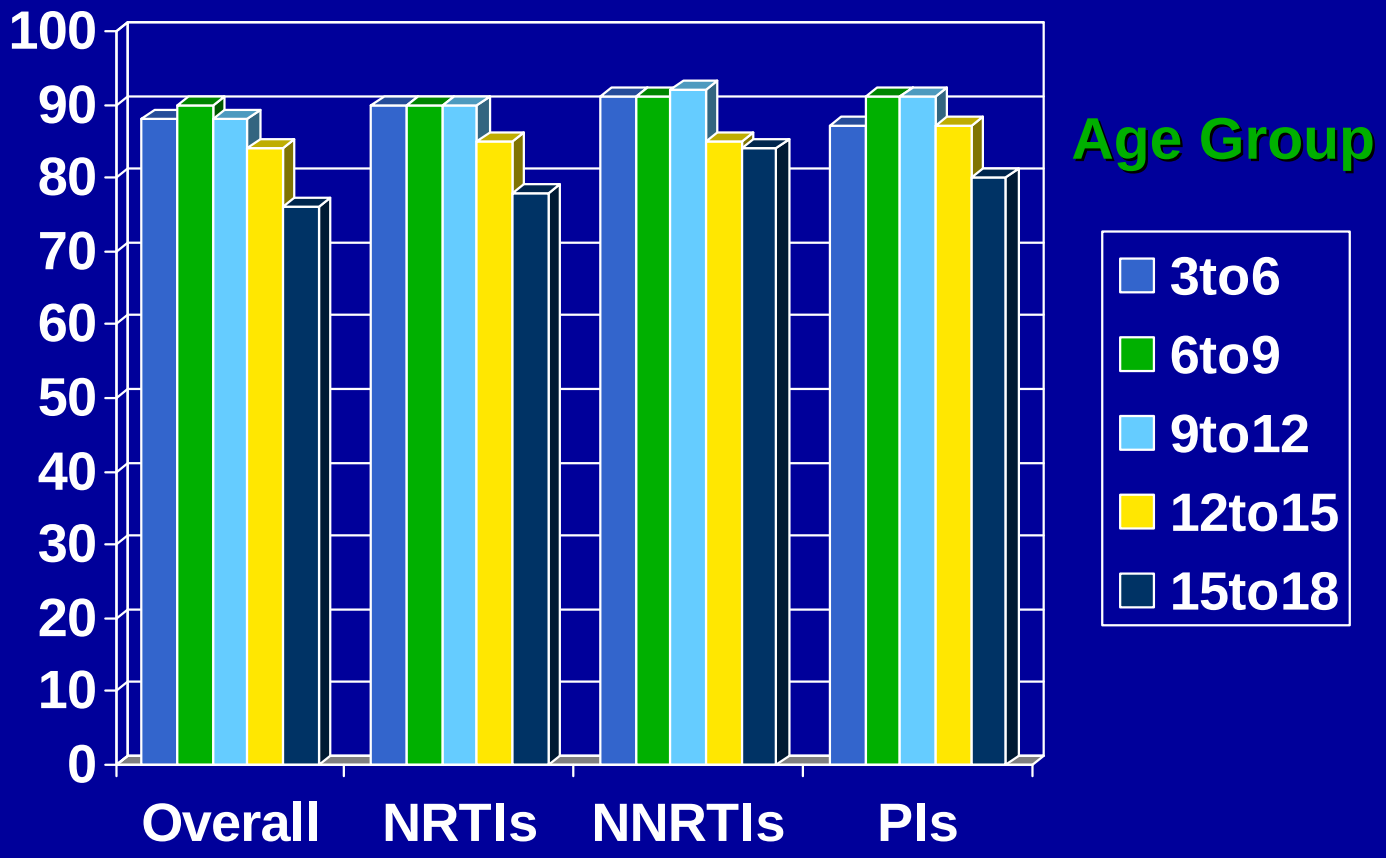


Psychosocial Characteristics

- **Person responsible for medication adherence:**
  - ❑ **biological parent** **609(29%)**
  - ❑ **relative or other adult** **705 (34%)**
  - ❑ **self (+/- others)** **772 (37%)**

Adherence is defined as not missing any doses of expected medications in last 3 days, as reported by person responsible for medication adherence.

Frequency of 100% Adherence by Age Group



Significant Predictors – Non Adherence

Child Factors

Age: Odds of non-adherence increase by 10% for each year of age.

Gender: Girls had higher odds of non-adherence.

Partially or wholly responsible for their own adherence had higher odds of non-adherence.

Depression or anxiety (3%) have almost twice the odds of non-adherence.

Academic difficulty (repeating a grade in school) is associated with higher odds of non-adherence

Significant Predictors – Non Adherence

Caregiver-environment factors

Recent stressful life event (e.g. financial, change in family structure) had increased risk for non-adherence

Better adherence is associated with presence of relative or other adult as primary caregiver (non-biological parent).

Better adherence is associated with higher caregiver education level.

- **Odds of non-adherence decrease by 20% for each increasing level of education of the primary caregiver.**

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Adherence Interventions

- Identify reasons for past non-adherence
- Assess current and potential barriers
- Choose the least complex regimen (e.g. avoid food complicating meds, reduce # and frequency of meds)
- Educate before regimen begins and at
  . every visit.
- Cue dosing to normal daily activities.

Adherence interventions

- Use adherence tools, such as a buddy system and pillboxes.
- Provide ongoing support and feedback to child/caregiver—share viral load results.
- If virologic response is not positive, prescribe drug holiday until new plan is possible.
- Integrate mental health, substance abuse and medical treatment.

Adherence Interventions

- Address stressful circumstances that compete for limited resources (e.g. care giving, housing).
- Use directly observed therapy (DOT)*
- Employ peer educators
- Anticipate, monitor, and manage side effects*
- Do dry runs with dummy medications before initiating complex ART therapy†

Adherence Interventions

- Integrated care strategies
- Multidisciplinary interventions are most effective
- Role of health care provider is central
- Mixed approaches work best (educational, behavioral, affective)

THANK YOU

Aging HIV+ children and adolescents (Mellins et al.)

- Born to high risk women with substance use histories and prevalent heritable psychiatric disorders
- Experienced multiple environmental stressors, including the potential death of a parent
- Extended period of less than optimal HIV medical care (pre-HAART)
- Aging into developmental stage of puberty and presentation of psychiatric disorder
- Behavior problems may be a major public health concern

MENTAL HEALTH AND RISK BEHAVIOR IN HIV+ YOUTH AND SEROREVERTERS

Claude Mellins, PhD
New York

Study Design: Observational study of 350 perinatally HIV-exposed 9-16 year olds and their primary caregivers interviewed at baseline and 18 month follow-up

N= 200 HIV+ and 150 HIV-

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- Externalizing disorders (Conduct Disorder, ADHD, and Oppositional Defiant Disorder), as well as phobias were most common .

- Family predictors: Caregiver mental health and parent-child relationship factors were related to child mental health outcomes ($p < .05$).

Sexual and Drug Use Behavior

- Onset of Sexual Intercourse was not common
  - 10 of 105 HIV+ youths (9.5%) and
  - 8 of 58 HIV- youths (13.8%)
- Substance Abuse Disorders were rare
  - No alcohol abuse;
  - 3 HIV- and one HIV+ youth met criteria for marijuana abuse.
- No HIV status group difference in rates.

Adherence

- Non-Adherence in the past month was prevalent (54% of youths)
- Non-adherence significantly associated with:
  - ❑ youth mental health (behavior problems) and family (e.g., parental monitoring) factors ($p < .05$)
  - ❑ marginally associated ($p < .1$) with having an HIV-positive caregiver and decreased caregiver supervision

Recommendations for work with families affected by HIV

Be sensitive to the fact that much shame and guilt is associated with HIV diagnosis, a multigenerational disease.

Interactions with unfamiliar people, institutions are very stressful.

Recommendations

- Be aware that disclosure of HIV diagnosis to child is not assured.
- Interview parent/caregiver separately to determine disclosure status.

Recommendations

- Be aware that HIV diagnosis may be only one of multiple significant life stressors, including poverty, history of loss, limited education, limited social support.

Recommendations

- Be aware that there may be family history of psychiatric illness, substance abuse, often untreated.

Recommendations

- Families affected by HIV need much support to access mental health care and much support to maintain care, once initiated.
  - Remembering appointments
  - Transportation
  - Feedback to them and other providers
  - Implementation

Section of Pediatric, Adolescent, and Maternal HIV Infection/CMH

- Family-Centered
- Multi-disciplinary Team
- Clinical Treatment/Clinical Trials
- Longitudinal Outcome Research
- Psychosocial support and advocacy

Psychological risk factors related to chronic illness

- **Coping ability and adjustment to chronic illness are affected by:**
  - The degree to which the illness impairs functioning and quality of life
  - Involvement of the brain
  - Type of medical procedures and hospital experience

Psychological Risk Factors in Chronic Illness

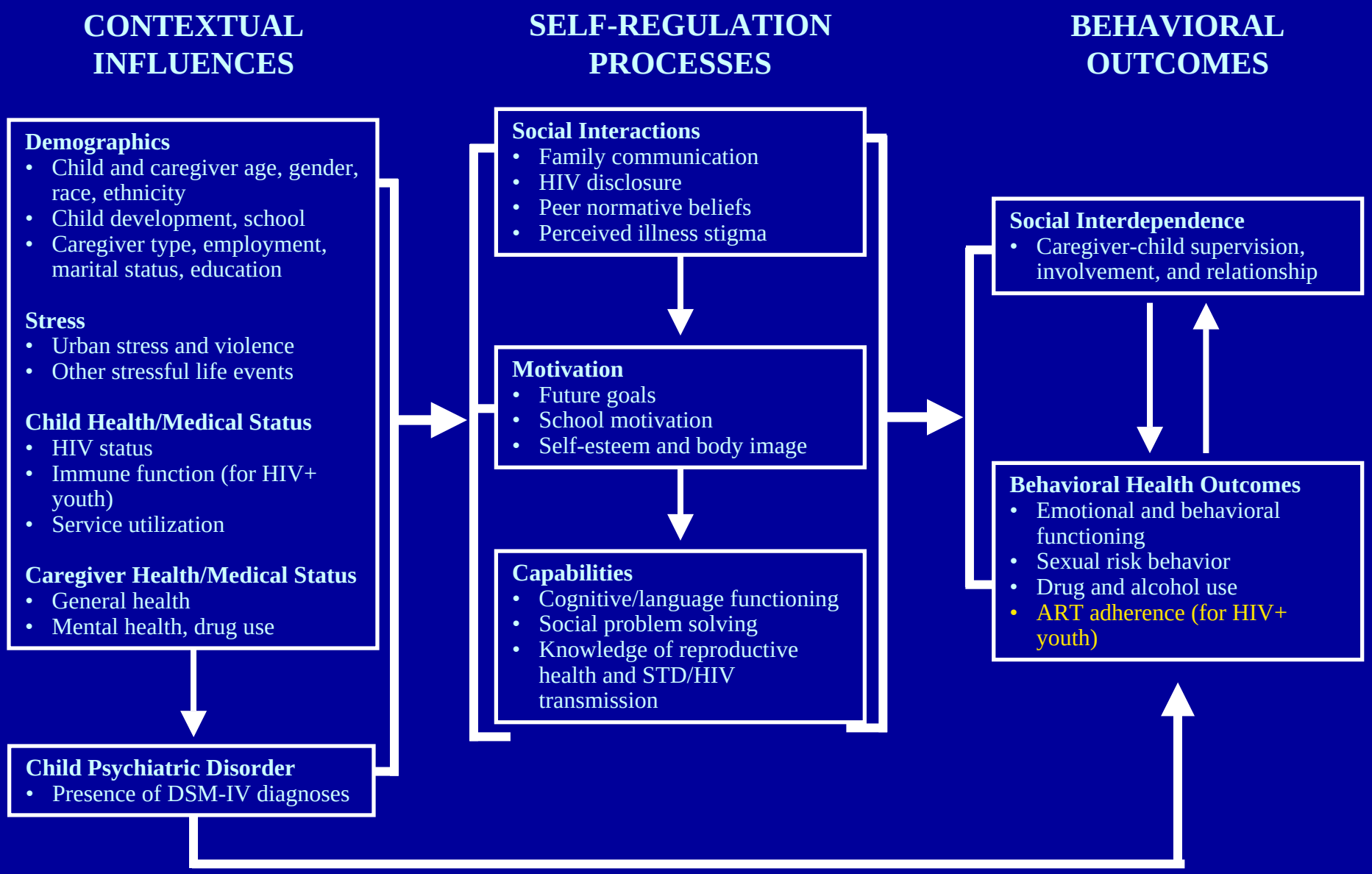
Coping and adjustment also related to:

-Individual characteristics and internal resources of child

-Family functioning

-External resources and social support systems

Behavior is determined by multiple factors (modified Social Action theory model)



Medication Adherence: A Major Challenge in HIV Infection

- 95 % of doses of antiretroviral medications must be taken to maximize virologic control
- Non-adherence is common

How many report 100% Adherence?

- **To whole ARV regimen (n=2088): 85%**

- To NRTIs (n=2067): 86%
- To NNRTIs (n=678): 89%
- To PIs (n=1318): 87%