



Fourth Annual
Iris House Summit
WOMEN
AS THE **FACE**
of **AIDS**
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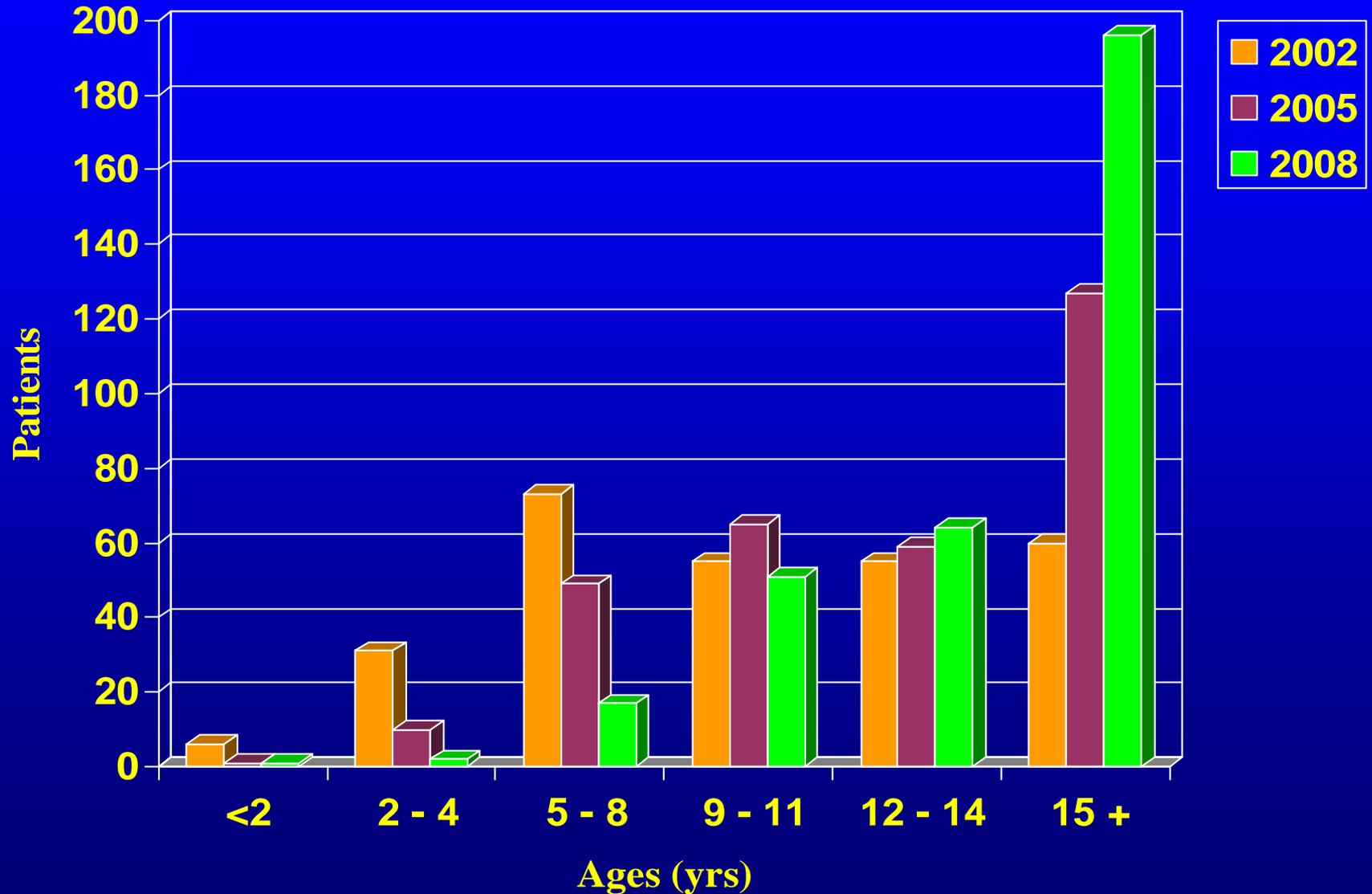
THE CHALLENGE OF TRANSITIONING CARE

PERINATALLY INFECTED CHILDREN
BEHAVIORALLY INFECTED CHILDREN

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Adapted from the original presentation prepared by
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HIV Infected Patients Jacobi Medical Ctr. 2002 - 2008



Pediatric HIV

Update

- Three unique Pediatric Populations
 - Vertically infected
 - Adolescents infected through high risk activities
 - Others: accidental needle sticks, non-consensual sex,
 - Contaminated blood products—clinical course similar to vertically infected
- US: maternal-infant transmission rate about 1%; approximately 250 infected babies/yr
- Aging perinatal population involved in at-risk behaviors

Transition into adult care

- Public Health organizations have made the transition of adolescents/young adults into adult systems a priority *
- Most institutions have no plan to accomplish this
- Most clinicians lack training in this
 - Most clinicians will never need to do this
- Relatively new task
- Models: CF, Sickle Cell anemia, spina bifida
 - 90% reach adulthood
- Now HIV

Not Just a Physical Transition

- Transitioning from:
 - Being defined by a poorly treated illness perceived as progressive with a shortened life expectancy
 - Having few expectations or responsibilities
- **TO**
 - A chronic illness that is treatable with an unknown but increasing life expectancy
- Personal redefinition: Transition from being defined by HIV to being defined as an individual living with HIV

Consensus Statement on Transition for Young Adults with Chronic Conditions

- “vision of a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system that is as developmentally appropriate as it is technically sophisticated”
- “goal of transition...is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood”
- More difficult for those with more severe conditions especially in light of **social, emotional and behavioral sequelae**

Policy Goals

What should be done

- By 2010, physicians providing primary or subspecialty care to young people with special needs should:
 - understand the rationale for transition from child to adult-oriented health care
 - have knowledge and skills to facilitate this
 - know if, how, and when transfer of care is indicated
- Transition needs to be **patient centered** requiring:
 - flexibility, responsiveness, continuity, coordinated and comprehensive

What is Meant by Transition?

- Transition from one health care provider and/or system to another
- Maintaining ongoing relationships with a change in orientation allowing development of age appropriate independence
- Most advocate that adults should have an adult-focused primary care physician
- Without communication and collaboration between pediatric and adult primary care clinicians and subspecialties, this will not be successful
- You need a plan!!!!

From Pediatrics to Adult Settings

Considerations

- What is best for the patient?
- What is best for the clinician?
- What is best for the other health care professionals caring for patient?
- What is best for the family?
- What is best for the institution?
- Short term and long term consequences
- Consequences of Consequences

Initial Steps to Consider

- Need a leader to start the process of transition who partners with patient, family, health care systems
- Identify needs for transition and start translating this into training of health care professionals
- Create a portable health care summary
 - HIV and confidentiality issues
- At age 14, create a written health care transition plan with patient, family, health care professionals
 - Update annually
 - Consider finances

Initial Steps to Consider (cont'd)

- Apply the same guidelines for primary and preventive care for all adolescents and young adults
- Anticipate that children with special health care needs may (will) require more resources and services than typically provided to different age groups
- Ensure affordable, continuous health insurance coverage for all young people with special health care needs throughout adolescence and adulthood
- Recognition of complexity of issue
- **Vertically acquired HIV may be uniquely complex and difficult**

Unique Issues for HIV-infected Adolescents/Young Adults

- Psychosocial
 - Predominately affects an urban minority population facing numerous socioeconomic challenges
 - Lack of resources: home, school, mentors, friends
 - Transitioning from an incurable illness to a chronic care model
- True familial illness: Generational HIV,
- Familial loss—Leading to the perception of life defined by abandonment:
 - Many mothers, fathers and others have succumbed to the illness
 - Many children are products of foster care system
 - Numerous changes in guardians and less stability in “parental” care

More Unique Issues for HIV-infected Adolescents/Young Adults

- Life characterized by **LOSS** and stigmatization
 - Loss of health during childhood
 - Loss of being treated as a normal child—
overprotection, lack of consistency, being coddled
as expected life expectancy was perceived as
limited
 - Loss of ability to experiment: Relationships, SEX,
Drugs, Ethanol
 - Loss of “being or looking normal”
 - Potential for disconnect between reality and the
perception of an adolescent
 - Great impact on function

Other Potential Environmental Co-Morbidities

- Familial substance use
- Familial Mental Illness
- Domestic Violence
- Abuse
- Stress
- Economics
- Stigmatization
- Stuff we don't even know about

Mental Health and Risk in HIV+ Youths (aka Project CASAH)

Claude Mellins (PI), E Brackis-Cott, E
Abrams, A Wiznia, M Bamji, A Jurgrau, M
McKay, many others and the participants

NIMH RO1-MH63636

Project CASAH

Perinatally infected adolescents

- Determine prevalence of Psychiatric Disorders (PD) and Behavioral Health Outcomes (BHO)
 - Emotional and behavioral functioning
 - Sexual behavior
 - Drug use
 - ARV adherence
- Examine association between HIV and PD and BHO using seroconverters as control
 - Hypothesis: living with HIV puts children at risk for above
- Identify risk and protective factors related to BHO over the 18 month observation period

Project CASA

- Population: 202 HIV+, 135 Seroreverters
- Ages 9-16 (50% 9-12 yrs)
- 5 year project in NYC, 4 medical centers
- Evaluations at baseline and 18 months later
 - 2 interviews per time frame
 - Based upon Social Action Theory
- Interview both youth and caregiver

CASAH

Preliminary Results

- 47% living with birth parent
- Income 57% < \$25,000
- Child Psychiatric Disorder
 - 62% HIV-infected with DSM IV diagnosis
 - 51% of HIV-exposed, uninfected with + DSM IV diagnosis
- Caregiver Mental Health Problems
 - Depression, Anxiety
 - Problematic parent-child communication
- Lots of unprotected sex—and early
- Implications on adherence

Project CASAH

Preliminary Significance

- Substantial mental health and behavioral problems in both HIV+ and SR
- Barriers to optimizing health and progression through life cycles
 - School
 - Peer relationships, development of healthy relationships
 - Employment
 - Potential barrier to successful transition
- Potential risk factor for others (sex, emotional lability)
- Inter-relationship between caregiver MH, child-caregiver relationship and outcome
- Need to address family and not just adolescent
- Implications for transitioning

Mental Health

HIV (perinatal) infected adolescents

- About 50% live with birth parent
- Child Psychiatric Disorder
 - About 66% have DSM IV diagnosis
 - Almost 50% of HIV-exposed, uninfected adolescents have a DSM IV diagnosis
- Major diagnosis
 - Depression
 - Anxiety
 - Behavioral Problems: Impulse control, ADHD
 - Cognitive Delay
 - Post traumatic Stress Disorder
- Caregiver Mental Health Problems
 - Depression, Anxiety
 - Problematic parent-child communication

Consequences

- High risk for poor outcomes through young adulthood, including difficulties functioning independently and advancing in life
 - Dropping out of school
 - Substance abuse, ETOH,
 - Incarceration
 - Not prepared for employment
 - Engaged in high risk behaviors
 - Their own health
 - Risk of transmission to others
 - Pregnancies
 - Further maternal-infant transmission
- High risk for non or intermittent adherence to ARV
 - Progressive immunodeficiency, increased viral resistance

Chronological Age Does Not Always Indicate Developmental Age

Expectations should be based upon
the reality of the developmental status

Adolescent Brain Development

Perspectives of an immunologist

- Limbic System: First part of brain to develop
- Limbic System= Raw emotion-
in overdrive in adolescents-hormone related
- Cerebral cortex, the judgment center, is the last part of the brain to develop
- Immaturity of cerebral cortex coupled with a hyperactive Limbic System leads to Poor Judgments
- Result is Risk Taking behavior driven by pleasure centers and a sense of immortality.

Typical Adolescent Issues

- Time of experimentation
- Uneasiness with appearances and associated changes and their functions-but curious
- Meeting and choosing peers and those associated pressures
- Sense of immortality, denial of danger
- Their “knowing (learning)” reality and need to fulfill their pleasure centers creates internal conflict
- This conflict (anxiety) is in conflict with their pleasure seeking drive and creates anxiety
- Denial (deflection) feels better (temporary)

Treatment Quandary

- Attempting to achieve a successful and sustainable antiretroviral therapy without focusing on the obstacles, barriers and reality facing the adolescent/young adult and their family and their social network is doomed for failure.
- HIV and its treatment are not very forgiving.
- Frequently, there is a real time bomb ticking
 - While waiting for proper time, higher viral loads are associated with progressive immunodeficiency and increased risk of transmission to others
- Temporary failure can have long term consequences
 - Resistance, intolerance, frustration, poor self-esteem
- The HIV infected adolescent may be putting him/herself at risk by not listening to the wized comments of caring the adults

The Treatment Quandary

- Not an easy task; no easy solutions
- An adult reasoning with an adolescent by insisting “do it this way because it is best for you” is doomed for failure as this is counter to fulfilling their desire pleasure centers, their drive for independence and the resulting latent anxiety.
- “To Kill a Mockingbird” Reality Test: put your feet in another person’s shoes, squish around awhile until you are comfortable, become them, then open your eyes and view the world from their perspective.
 - Do this, then insist, prescribe, etc.
 - Credit to Harper Lee (author) or Gregory Peck (Atticus in the movie)

Programmatic Approaches Adolescent Care

- Keep your program open. If an adolescent is engaged on any level, they are buying into part of the health care message. Some suggestions:
 - Open access to personnel
 - Clinics that do not interfere with their lives
 - What do they want (consumer involvement)?
 - Do not impose traditional medical models
 - Gatherings, events, “hanging out”, tutoring
 - Multimedia: email, web sites, internet access, educational software
- Be non-judgmental (yourself and your system)
- **Keep them involved. They need to decide.**

Existing Programs

- Pediatric HIV Programs
 - Many are described as the “Cadillac” of programs (hopefully Hybrid technology)
- Adult Programs
 - Many are stretched to the limits
 - Especially limited case management, mental health capacity
 - Adult Clinicians are
 - Very Busy
 - Not trained in transition
- What is the best for the patient?

Transition

Pro

- Normal developmental stage
- Movement into independency and taking control and responsibility for life
- Considerations stated in consensus document (discussed previously)

Transition

Reasons for a Cautious Approach

- Incredibly vulnerable population
- Challenges unrivaled
- Significant negative consequences associated with being loss to follow-up, even if it is temporary
- Life defined by loss
- Imposition of loss of continuity with past
 - Many pediatric programs/clinicians represent the most significant ties to the patient's past
- Co-morbidities: especially mental health
- Constraints on systems trying to transition

Moving Forward

- While HIV is a chronic illness; challenges are unique with concerns spanning the entire spectrum of medical and psychosocial issues for the adolescent/young adult and the family
 - Not only the infected individual but also affected populations
- Standardized approach or individualized local approaches?
 - Complete physical transition vs. blended transition
 - To be successful, transition will need to be deliberate
 - Consideration of HIV specific needs, local considerations and expertise
- Unique Models and flexible time lines:
 - Gradual Transition
 - Blended Transition
 - Never Transition—just augment programs

Parting Thoughts

- Need for multidisciplinary discussions to explore options
- Unrealistic to believe that any one model will be right for all programs and all patients
- Need for study and sharing ideas
- Planning and communication are vital
- Need to develop metrics to measure success and failures
 - How much failure is acceptable
 - Modify plans, as needed
- Novel challenges require novel and flexible systems



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Mental Health and HIV: What's the Connection?

June 20,2009

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OBJECTIVES

- **Is the psychosocial important? Is just more work? (to be answered at the end of the discussion)**
- **Understand the prevalence of mental health disorders and PLWHA (the dual/triple diagnosis) and its impact on treatment adherence.**
- **Discuss assessment of common mental disorders.**



Overall Prevalence of Mental Health Disorders

- The National Institute of Mental Health suggests that within a given year, 26.2% of Americans have a diagnosable mental health disorder. The impact on lives is incalculable.



HIV Prevalence (1)

- **Highest rates of HIV infection were in Clients with dual diagnosis of severe mental illness and substance use disorder**
 - **18.4% overall prevalence**
 - **33.8% among injection drug users**
 - **15.4% among non-injection drug users**
 - **10.9% among alcohol users**
 - **2.5% among those with no substance abuse**

(Cournos and McKinnon, 1997)



Assessment and Screening (1)

mental disorders of concern in PLWHA

- ❑ **Medication-related mental disorders**
- ❑ **Substance-induced mental disorders**
- ❑ **HIV-related mental disorders**
- ❑ **Neurocognitive deficits**

(Batki & Selwyn, 2000)



Common mental disorders among individuals with HIV and substance abuse

- **Adjustment disorders**
- **Sleep disorders**
- **Depressive disorders**
- **Mania**
- **Dementia**
- **Delirium**
- **Psychosis**
- **Personality disorder**

(Batki & Selwyn, 2000)



Somatic Symptoms

- ❑ **PLWHA experience somatic symptoms**
- ❑ **Rarely life threatening**
- ❑ **Occur frequently**
- ❑ **Often overlooked**
- ❑ **Difficult to treat**
- ❑ **Adversely affect quality of life**
- ❑ **Often co-exist with medical and psychiatric disorders**



Somatic Complaints

- **Insomnia**
- **Pain**
- **Poor appetite**
- **Weight changes**
- **Sexual dysfunction**
- **Fatigue**
- **Stomach pain**



Initial Mental Health Assessment

1. Developmental/Social History

- 1. Childhood trauma or illness**
- 2. Education**
- 3. Employment**
- 4. Sexual orientation**
- 5. Relationship history**
- 6. Current support system/social network**



Initial Mental Health Assessment (2)

. Family

- 1. Family relationships**
- 2. Family psychiatric history**
- 3. Family substance abuse history**



ASSESSMENT CONT

3. Medical History

1. HIV history:

- a) Date of diagnosis**
- b) Stage of disease**
- c) Most recent CD4+ T cell count**
- d) Most recent viral load**
- e) HIV-related illnesses**

2. Other medical illnesses

3. Current medications



ASSESEMNT CONT.

4. Substance Abuse History

- 1. Age of onset of substance abuse**
- 2. Substance abuse description**
- 3. Substance type**
- 4. Amount, frequency, and route of administration**
- 5. Past or current substance abuse treatment**
- 6. Involvement with self-help (e.g., AA, NA)**



ASSESEMNT CONT.

5. Psychiatric History

- 1. Age of first psychiatric problems**
- 2. Outpatient treatment**
- 3. Inpatient treatment**
- 4. Past and current diagnosis/diagnoses**
- 5. Past and current medications and responses**



ASSESEMNT CONT.

6. Current Psychiatric Symptoms (cont.)

6. Emotional instability

7. Anxiety (acute or chronic)

8. Symptom pattern (episodic; e.g., panic attacks vs. generalized)

9. Psychotic symptoms (e.g., thought disorder)

10. Hallucinations

11. Delusions



ASSESEMNT CONT.

- . Danger to Self or Others**
 - 1. Ability to care for self**
 - 2. Suicidality**
 - 3. Assaultive/homicidal ideation**



Barriers to Treatment: Triple Diagnosis

- **HIV, Substance Abuse and Mental Illness**
- **Factors that contribute to delayed entry, or lead to dropping out of care include:**
 - **Poverty**
 - **Unstable housing**
 - **Lack of resources**
 - **Complexities of the system e.g.lack of trust**



Barriers to Treatment

- **Injection drug users are less likely to receive ART than any other population**
- **Factors associated with poor access to treatment include**
 - **Active drug use**
 - **Younger age**
 - **Female gender**
 - **Sub-optimal health care**
 - **Not being in a drug treatment program**
 - **Recent incarceration**
 - **Lack of health care provider expertise (DHHS, 2006)**



Why the Psychosocial ?

- Empowers you as the CM
- Can help you understand the client's barriers to treatment
- Assist with your assessment of needs as well create an appropriate service plan



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