

Having Sex, Having Babies, and Transitioning to
Adult Care:
Providing Care to Adolescents and Young Adults
with Perinatal HIV Infection

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Background

- Prior to the mid 1990's, few children with perinatally-acquired HIV survived into young adulthood. Now these adolescents and young adults are transitioning to adult care.
- Compared to other chronic illnesses of childhood, little research has documented the impact of HIV infection on adolescents and young adults
- HIV infection presents unique challenges such as cognitive functioning, mental health, body image, sexuality, stigma, mortality, and disclosure that may affect adherence and health outcomes.

Developmental Tasks

(Erikson, 1959; 1980)

- Adolescent tasks
 - Physical maturity
 - Emotional development
 - Membership in peer group
 - Sexual relationships
- Young Adulthood tasks
 - Stable relationships
 - Childbearing and rearing
 - Career

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Methods

Inclusion criteria

- Diagnosis of perinatal HIV infection
- Age 18-24
- English speaking

Recruitment

- Flyers at Pediatric ID & Immunology Clinic
- Purposive sampling

Procedures

- UM IRB approval
- Data collection at clinic
- Interviews of 1.5-2 hours
- Interview guide with field notes
- Compensated \$50

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Sample Characteristics (N = 25)

VARIABLE	RESULT
Sex	Females = 11 Males = 13
Age	18-24 years
Race/Ethnicity	African American = 18 Hispanic = 3 Haitian = 2 Bahamian, Jamaican, African = 1 each



Sample Characteristics (cont.)

VARIABLE	RESULT
Education	In high school = 3 < HS education = 6 Diploma/GED = 8 In college = 5 In trade school = 2
Receiving ART	Yes = 19; No = 5
Most recent CD4+ count	Unknown = 17 < 200 cells/mm3 = 6 > 200 cells/mm3 = 1
Most recent HIV RNA	Unknown = 10 Detectable = 7 Undetectable = 5 52-96,000 copies/ml



Physical Health Issues

- Body image changes from medications
- Adherence



“Some people look at me (and) they don’t know that I have HIV because I don’t look sick at all...That’s one thing I am really happy about. I don’t want to walk down the street and people say, ‘Why are you sick? Why do you look like that?’ ...It would make me feel really bad.”

Mental Health Issues

- Coping
- Mental illness
- Substance abuse
- Reading/learning disorders



“My situation makes me feel depressed. Like I can’t clearly explain my case...I am concerned about my son...I can’t let my life revolve around HIV. You have to survive, especially if you have kids...I can’t be depressed and be sitting there, you know? My child is going to be depressed too, and I can’t take that.”

Psychosocial Issues

- Disclosure of HIV infection to others
- Family communication and family dynamics
- Stigma from the community and the church
- Wanting to talk about HIV



“Because when I was young my mother told me never to talk about it...Well, then I was stuck in a rut where I wasn’t supposed to talk about it, (and) it was really hard because I wanted to talk about it...It was one of those things that I just held inside of me. And it was one of those things that I just wanted to talk about. I wanted to say it out loud.”

"When I went to church they were like, 'Oh yeah, this is the guy who has it.'...Don't feel sorry for me. I don't go to church anymore because they talk too much. I'm not into that, you know? You're in the church of God. You're supposed to be worrying about church and God. You don't need to worry about everybody else's business."

Sexual Health Issues

- Concern about reproductive health, especially pregnancy
- The reality of sexual disclosure
- Sexual relationships and STIs
- High risk sex



"The first time I had sex, I didn't use a condom, but after I started dated I wore a condom. But I said, 'Damn! Because I know the law says that you should tell the girl, even if you don't want to tell the girl. You should always tell the girl.' She could have it and then I could go to jail for life. Damn! I'm praying to God that she doesn't have it!"

"I've never had sex. I've dated guys, but I never got too attached. I'm always distant...I never got deep in a relationship. I never introduced him to my family. If I got too attached, someone is going to hurt me and then they are going to leave me anyway."

Other Sources of Risk

- Commercial sex work
- IV drug use
- Community violence
- "Fast money (Hustling)"

Transition

- Negative aspects of transition.
- Positive aspects of transition.
- "I don't want to leave my 'family'."
- "...I'm not sure they are going to care as much in the adult clinic."

"Things change. I got to keep going because I am getting older. Over here they help you too much. It's kind of bad because when the kids get older and go to the other clinic, they aren't prepared to do a lot of things on their own...They ain't going to play with you there."

"I'm used to people caring and I'm not sure they are going to care as much at the adult clinic. Since you are an adult, you are supposed to take care of yourself."

"Just look at us. We are doing well and living longer. We don't have to be in the hospital anymore. Yes, I will be leaving here and I will feel mixed about it."

Implications for Care

- Growth and development issues
- Communication
- Awareness of reading/comprehension issues
- Adherence (and accepting non-adherence)
- Assist with family dynamics issues
- Assessment of other sources of risk

Implications for Care (continued)

- Focus on reproductive health
- Assist with disclosure
- Assist with sexual negotiation
- Mental health screening
- Substance abuse screening

Implications for Care (continued)

- Providing care vs. enabling
- Life skills
- Mentoring
- Transition as a process, not an event

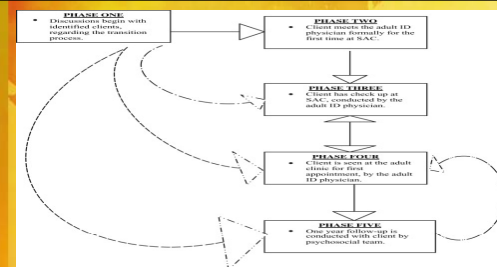


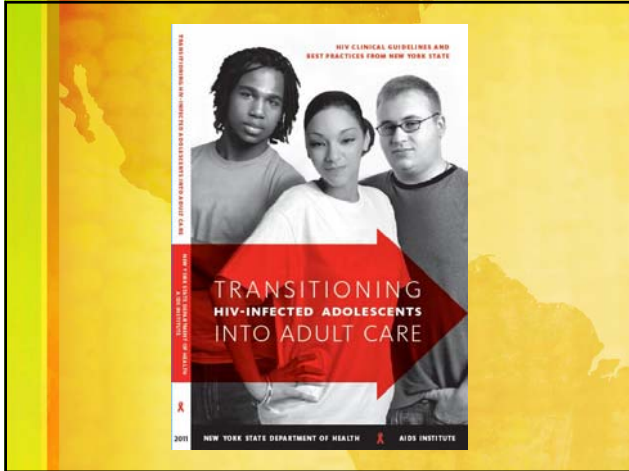
Figure: The "Movin' Out" transitioning model.

Maturo, D., Powell, A., Major-Wilson, H., Sanchez, K., De Santos, J.P., & Friedman, L.B. (2011).

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Thank You!

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