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HIV-AFFECTED FAMILIES: DEVELOPMENTAL CONSIDERATIONS & FAMILY INTERVENTIONS

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Prevalence of HIV

- Increase in new cases of HIV in women & female adolescents
  - Between 2000 & 2006, no. of women with HIV increased 55%
  - New cases of HIV in females in 2007 = 10,977
  - HIV transmission routes: IVDU decreasing; high-risk heterosexual contact increasing
- Disproportionality in women & female adolescents
  - Rate for Blacks more than 18 x Whites
  - Rate for Hispanics nearly 5 x Whites
- Incidence of HIV/AIDS in children (under 13)
  - Perinatal transmission declined by 95% in past decade
  - New cases of pediatric HIV in 2007 = 159
  - Racial profile: 67% Black, 15% Hispanic, 13% White

Source: Centers for Disease Control and Prevention, 2009

Childbearing & Child Rearing

- Women with HIV living longer, healthier, & have a wider range of reproductive choices
- Decision to have children: 12% conceived/bore post-diagnosis
- Births in women with HIV/AIDS: 8,650-8,900 in 2006
  - 30% higher than in 2002
- In nationally representative sample, 28% of infected adults had children (35,000 families)
- Women with perinatally acquired HIV disease are of reproductive age & sexually active

Sources: Schuster et al., 2000; Whitmore, Zhang, & Taylor, 2009

Family Focus

*"HIV is a **family** disease."*

~

"Almost inevitably, when you identify an individual with HIV, you will find that other members of his or her family and/or household are also HIV-infected."

~

"For all types of families, across both developed & developing nations, the impact of an individual's HIV infection radiates across the entire family system."

Sources: ICAP, Columbia University Mailman School of Public Health; Rotheram-Borus, et al (2005)

Concomitant Social Risk Factors in Families

- Substance abuse (including excessive drinking)
- Poverty/unemployment/lack of health insurance
- Unmarried/unstable relationships
- Intimate partner violence
- Victims of crime
- Lack of social support
- Low educational attainment
- Poor housing
- Lack of transportation/childcare
- Mental health threats & problems

Sources: HIV/AIDS Bureau (2004); AIA Resource Center Fact Sheet (2009)

Circumstances in Neonatal Period

- Childbirth may be *the* occasion when mother learns of her HIV status.
- HIV diagnosis is a traumatizing event.
- Trauma heightened by simultaneous diagnosis of mother & child.
- Distrust establishment re: diagnosis, treatment & solutions
- HIV conspiracy theories in minority community
- Denial of HIV disease
- Mother/infant dyads at increased risk for impaired bonding

HIV-related Burdens & Stressors

- Chronic illness & physical health symptoms
- Challenging medication regimens
- Distress re: own health & life expectancy
- Concerns re: childrens' future & custody
- Stigma & social alienation
- Disclosure difficulties (particularly to children)
- Fears re: spreading HIV infection in the household
- Depression, anxiety, guilt
- Uncertainty re: infant's HIV status
- Special needs/care for diagnosed HIV-infected child

Opportunities & Protective Factors

- Childbirth -- often a window of opportunity
- Mothers may embrace maternal role & want what is best for their infants & families.
- Mother may be willing to accept help.
- HIV diagnosis may provide impetus for women to adopt changes in self-care.
- Opportunity to gain entry & engage other family members.
- Potential impact on interaction between mother & child.
- Potential impact on early development & health of infant.
- Nurturing/stimulating home environment can mitigate negative birth outcomes.

Source: ICAP, Columbia University Mailman School of Public Health

Duke University & UNC, Chapel Hill Studies Developmental Outcomes of Infants of HIV+ Mothers

- Longitudinal study on parental caregiving of infants of women with HIV.
- Goal: identify factors that place infants at developmental risk & potential interventions
- Parental caregivers: Southern, poor, rural, African American, single.
- Infants: younger than 6 mos. & seropositive for HIV.
- Variables: **child characteristics** (preterm, gender, HIV status); **caregiver characteristics** (caregiver consistency, education, depressive symptoms); **family characteristics** (conflict, number of children, caregiver partner status); **parenting quality** (positive attention, negative control)
- Data collection: enrollment (e.g., 3 mos old infant), 6, 12, 18 & 24 mos.

Source: Holdich-Davis, Miles, Dandor, Burchinal, O'Donnel, McKinney, Lim (2001)

Assessment Instruments (Duke/UNC study)

- **Depression:** Center for Epidemiologic Studies Depression Scale (CESD)
- **Family:** Family Environment Scale
- **Parenting:** Naturalistic observation of behavior
- **Home environment:** Home Observation for Measurement of the Environment
- **Child outcomes:** Bayley Scales of Infant Development-2nd edition (Mental Development Index & Psychomotor Development Index)
- **Language:** Preschool Language Scale, Version 3
- **Adaptive behavior:** Vineland Adaptive Behavior Scale

Source: Holdich-Davis, Miles, Dandor, Burchinal, O'Donnel, McKinney, Lim (2001)

Outcomes (Duke/UNC study)

- **Findings:** Both parenting quality & consistency of primary caregiver influenced developmental outcomes.
- Positive attention from caregiver – strongest/most consistent relation to outcomes.
- Higher mental, motor & adaptive behavior scores associated with more positive attention & more negative control.
- Infants with changes in primary caregiver had lower motor & adaptive behavior scores
- Development of infants related to their caregiving environments

Source: Holdich-Davis, Miles, Dandor, Burchinal, O'Donnel, McKinney, Lim (2001)

Duke/UNC Outcomes (cont.)

- High % of mothers at risk for depression.
- Depression re: feelings of stigma, perceptions of health, health problems
- Chronically depressed mothers -- less protective toward infant, less positive interactions, lower quality of home environment.
- Mothers denied their illness, avoided dealing with it, visited health care providers sporadically.
- Mothers put children's need 1st & focused on their maternal role to the exclusion of own needs/health.

University of Pennsylvania, School of Nursing Study

- Evaluated mother-infant interaction in southeastern U.S. in presence of maternal HIV infection.
- Compared groups of mother-infant dyads: HIV+ and HIV- mothers
- Goal: Determine whether maternal HIV infection was associated with differences in quality of mother-child interaction.
- Quality of interaction: Nursing Child Assessment Teaching Scales (NCATS)
- Maternal, child & environmental factors: interview form, CESD Scale & Bayley Infant Neurodevelopmental Screener.
- Findings:
  - No significant difference in mother-child interaction between the HIV+ and HIV- groups. (Both groups below normative samples.)
  - Despite more depression with HIV+ mothers, no significant influence on mother-child interaction scores between groups.

Promising Practices for Family Intervention

- Provide more information about HIV diagnosis & emotional support.
- Promote the physical and emotional health of mothers.
- Provide realistic, optimistic information about child's health trajectory.
- Support ethnically appropriate parenting.
- Assess role/ability of father & grandparents (for alternate care).
- Assess infant's status using developmental screening tool.
- Identify developmental milestones/timeframes for achievement.
- Discuss caregiver perceptions of infant's capabilities.
- Observe infant/parent interactions.
- Encourage/support family efforts to care for the infant.
- Encourage verbalization of feelings by parent/family member.

Source: Holdich-Davis, Miles, Dandour, Burchinal, O'Donnel, McKinney, Lim (2001)

Cultural Context for Interventions

- African-Americans
  - Interventions that stress a "family ecological" approach rather than a "person-centered", approach will reducing psychological distress and family-related hassles.
  - Social network (extended family, community members, friends) often serves as powerful source of support.
  - Increase ethnic pride and knowledge of historical barriers; promote positive self-esteem and self-worth.
  - Empower African American women to be directly involved in prevention and intervention programming.
- Latinas
  - Service strategies that reflect universal Latino cultural values/beliefs (honor family)
  - Help in coping with the perceived stigma of the disease.
  - Addressing traditional cultural beliefs that pose barriers to disclosure.
  - Counteracting mothers' beliefs that they have not lived up to ideal motherhood.
  - Introducing infant massage as an alternative to breast feeding.

Source: Szapocznik, et al , 2004 ; Burchinal et al, 1996 in Klein, et al, The Source, Fall 09, Vol. 19, No. 2

The Health Federation of Philadelphia Family Centered Home Visitation Program

Goal: Strengthen families' abilities to provide safety, permanency & context for healthy development and well-being.

Approach: Combines trauma specific interventions with infant mental health & child development services. Culturally competent & accessible services delivered by multidisciplinary team, using a home-based model, in collaboration with hospital and community-based organizations.

Population: Low-income families infants & toddlers (0-3) infected/affected by HIV/AIDS, HIV positive pregnant and parenting women (age 13 & older), other family members/caregivers.

Services: Child development, parenting support, mental health intervention, health & nutrition monitoring, referrals (e.g., EI, CPS, education, legal, & community service)

Research: LSP Health Care Literacy Cluster; KIPS; Edinburgh Postnatal Depression Scale, Epidemiological Studies Depression Scale; SHIF

The Health Federation of Philadelphia Family Centered Home Visitation Program (cont)

- Outcomes:
  - 86% of families have alternative caregivers for children
  - 80% of families utilized appropriate health care services (prenatal, pediatric, HIV care)
  - 84% of parents/caregivers demonstrated satisfactory quality of parenting behavior adapted to their children's needs
  - 97% of infants/toddlers showed satisfactory social-emotional development
  - 48% of women/caregivers showing symptoms of depression improved
  - 94% of parents/caregivers provided satisfactory home environment (safety, permanency, child well-being)
  - 82% of families accessed family/community resources for meeting material, concrete needs

The Family Center Early Support for Lifelong Success

Goal: Assist children living with HIV+ parent in achieving age-appropriate developmental milestones & educational goals

Approach: 18-mo intervention targeting well-being, school readiness & safety of infants & young children perinatally exposed to HIV.

Population: HIV+ mothers or caregivers & their children aged 0-7 years in NYC

Services: Families w/ kids 0-5: early intervention services; Families w/ kids 4-7: educational advocacy services; Parents/caregivers: child development & parenting education; Content-centered workshops, classes, and programs; Play therapy for kids 2-7 experiencing trauma/loss. Referral services, permanency planning services, HIV medical case management, recovery groups for substance-using women

Research: Descriptive evaluation design, pre/post. Comparisons among naturally-occurring groups (i.e., HIV solely vs. HIV/ATOD caregivers). **Child outcomes:** placement in appropriate educational settings; decreased internalizing and externalizing behaviors. **Parent/caregiver outcomes:** Increased knowledge about their children's development; maintenance/improvement of physical & mental health; increased access to supportive services; reduced stress & depression

Gaps in Research & Services

- Need for more research focusing on early intervention/child development for young children 0-5 in families affected by HIV/AIDS
  - Better HIV treatment outcomes may result in changing needs of population.
- Need for more interventions with a focus on early child development/attachment
- Need for rigorous studies that utilize control groups

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