

Mental Health of People with Vertically Acquired HIV

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Introductions





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Ice Breaker



Learning Objectives

- Describe the various factors that negatively impact the mental health of people born with HIV and, more specifically, how their unique experiences have created a distinct sense of isolation for this community
- 2. Describe how social connectedness can positively impact the mental health and overall well-being of people born with HIV
- 3. Identify opportunities to support social connectedness among people born with HIV in both clinical and community settings



History & Context

Perinatally acquired HIV recognized in 1982



Unexplained Immunodeficiency and Opportunistic Infections in Infants --New York, New Jersey, California

CDC has received reports of four infants (under 2 years of age) with unexplained cellular immunodeficiency and opportunistic infections.

Case 1: The infant, a black/hispanic male weighing 5 lb 14 oz, was born in December 1980 following a 36-38-week pregnancy. Pregnancy had been complicated by bleeding in the fourth month and by preeclampsia in the ninth month. The infant was well until 3 months of age, when oral candidiasis was noted. At 4 months, hepatosplenomegaly was observed, and at 7 months, he had staphylococcal impetigo. Growth, which had been slow, stopped at 9 months. Head circumference, which had been below the third percentile, also stopped increasing. At 9 months, serum levels of IgG and IgA were normal; IgM was high-normal. T-cell studies were normal, except for impaired in-vitro responses to Candida antigen and alloantigen.

At 17 months of age, the infant had progressive pulmonary infiltrates, as well as continuing oral candidiasis, and was hospitalized. Mycobacterium aviumintracellulare was cultured from sputum and bone marrow samples. A CAT scan of the head revealed bilateral calcifications of the basal ganglia and subcortical regions of the frontal lobes. Repeat immunologic studies done at age 20 months showed lymphopenia, decreased numbers of T-lymphocytes, and severely impaired T-cell function in vitro; immunoglobulin determinations are pending. The infant remains alive and is receiving therapy for his mycobacterial infection.

The infant's mother, a 29-year-old resident of New York City, gave a history of intravenous drug abuse. Although she was in apparently good health at the time of the infant's birth, she developed fever, dyspnea, and oral candidiasis in October 1981. One month later, she was hospitalized and died of biopsy-proven Pneumocystis carinii pneumonia (PCP). She had been lymphopenic during the hospitalization; further immunologic studies were not done. At autopsy, no underlying cause for immune deficiency was found.

Rates of perinatal HIV cases in the U.S.



From CDC 2013

Figure 33. Persons living with diagnosed, perinatally acquired HIV infection, year-end 2020 (COVID-19 pandemic)—United States and 6 dependent areas



N = 12,588

CDC Surveillance Report, 2020





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Long term Survivor Characteristics in 80s-90s

Adults:

- Shortened life expectancy
- Loss of friends/partners
- Side effects of early treatment
- Challenges with adherence
- Drug resistance
- Stigma, shame, and secrecy

<u>Children:</u>

- Life expectancy in 1994 was 7.2 years and increased to 18.2 by 2006
- Loss of parents and/or siblings and childhood friends
- Treatment experienced by teenage years leading to resistance
- Co-occurring disorders/illnesses
- Exclusion from school, group activities, etc.
- Some did not know their status until late adolescence



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HIV Services for Children and Adolescents in 90's-early 2000's

- Awareness and concern about pediatric & perinatal HIV
- Specialty pediatric care:
 - Infectious disease pediatricians
 - Adolescent medicine supported us through young adulthood
- Summer camps for kids living with or affected by HIV
- Support groups & social activities
- Networks through services for women





Impact of ARTs on Perinatal Population

- New perinatal cases became rare
- Longer life expectancy for perinatal population
- Aging out of pediatrics/adolescent medicine into adult medical care
- Shrinking/stagnant size of population
- Previously mentioned awareness and concern disappeared
- Opportunities for social connections disappeared





Impact on Mental Health

- Overall, children and adolescents living with HIV had poorer neurodevelopmental outcomes
- 25% prevalence of mental health problems among children and adolescents with perinatal HIV, well above that of the general population
- Depressive symptoms in adolescents were best predicted by a combination of negative coping skills and poor neuropsychological functioning
- Key developmental tasks during adolescence:
 - Identity development
 - Build independence
 - Consider the future in terms of career, relationships, families, housing, etc.

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Impact on Mental Health

- Unexpected adulthood
 - Delayed milestones "what am I doing now?"
- Physical impact of long HIV
- Inherited trauma from parents
- Isolation
 - Lack of focus or mentions of this population
 - Not relating to other adult communities

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So what helps?

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Protective Factors

- Mental health services
- Socioeconomic support
- Holistic case management services
- Social Connectedness



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Social Connectedness

"Social connectedness is defined as the sense of belonging and subjective psychological bond that people feel in relation to individuals and groups of others"

Encyclopedia of Geropsychology (2015)

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Benefits of Social Connectedness

- Improve health outcomes (physical health & mental & emotional wellbeing)
 - Lower levels of anxiety and depression
 - Higher self-esteem and greater empathy for others



Social connectedness generates a positive feedback loop of social, emotional and physical well-being



- Framework that highlights how social identity and social connectedness enhances health
- Beneficial effects of social relationships for cognitive (Haslam et al. 2014b) and mental (Cruwys et al. 2013) health
- Social identification underpins positive forms of influence and support, groups will tend only to enhance health when (and to the extent that) their members identify strongly with them
- If these groups provide a person with stability, meaning, purpose, and direction, then this will typically have positive implications for that individual's mental health



Challenges in Sense of Belonging

- We are like unicorns
 - "You're the only one I know"
 - "I honestly thought you all died"
- Don't fit into age-defined spaces
- Unique experiences
- "Small" population





Our Response





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What Support We Need

- Financial support to create our own spaces
- Mentoring support
- Facilitation to support connections
- Camps for us as adults
- Trainings for staff on our community
- Research and data



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How can YOU help within your role and local or national or international community?

What CAN you do?

What do YOU commit to doing?





Thank you!

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