

HIV/AIDS AMONG CHILDREN AND ADOLESCENTS

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Epidemiology, Risk Factors, and Consequences

One million out of the seven million people with AIDS worldwide are children and adolescents, and 2 million children and adolescents have died from AIDS worldwide, with 90 % of those infected worldwide living in developing nations. Half of the approximately 6 million infections diagnosed worldwide annually occur among people 15 to 24 years, while approximately 25% of the 40,000 new infections per year in the United States occur in people 13 to 21 years of age. In the United States, the rates of mortality from HIV/ AIDS have decreased in people under 24 years of age but the hopes presented by new treatments and preventive efforts have been darkened by the continuous increase in risk reported amongst American youth (1, 3, 5, 5a).

Pediatric AIDS is seen disproportionately amongst children of color. Of the 3,788 children under the age of 13 living with AIDS in 2003, 570 were non-Hispanic white, 2,461 were African-American, 853 were Hispanic/ Latino, 17 were Asian-American, and 10 were American Indian. The children that run the highest risk of infection from HIV infected mothers are infants born to mothers who are prostitutes or intravenous drug users; mothers whose sexual partners are bisexual, have hemophilia or abuse of drugs; infants with a history of blood transfusions; and infants who have hemophilia. Children can also become infected with HIV through the exposure to needles without sterilizing, or by breast-feeding from an infected mother. Most cases among children and youth in the United States occur in the coastal states and in large urban areas. Socioeconomic and cultural factors amongst Latinos and African-Americans, such as poverty, high drug use, and sexual lifestyles are also factors in the prevalence of AIDS amongst their

descendants (5a, 6, 7).

Based on current trends, a young person age 13 to 21 is infected with the HIV virus in the United States every hour of every day. HIV spreads sexually amongst the adolescent population more than in any other group. Adolescents who are homosexual, who use drugs, youthful offenders who drop out of school or run away from homes, and immigrant youth are especially vulnerable to HIV infection. These youth are frequently difficult to reach through prevention and education efforts, and have limited access to medical insurance. African-Americans and Latinos are disproportionately represented amongst adolescents contracting HIV infection, accounting for over 85 % of AIDS cases in 2002. Adolescent females also represent a higher proportion of new HIV and AIDS cases, with 50% of new cases between ages 13 to 19 compared in 2002, and 66 % of adolescent females infected in heterosexual encounters. School drop-outs constitute approximately 3 million adolescents in the United States (12.7%) and are primarily youth of color. This group of youth has a high frequency of behaviors (particularly unprotected sexual activity and intravenous drug use) that place them at risk for contracting HIV or some other sexually transmitted disease, and are least accessible to prevention programs (1, 2, 3, 4, 5).

AIDS is the seventh leading cause of death among children from 1 to 4 years of age, and the sixth main cause of death between ages 15 and 24 years of age in the United States. The first children infected with HIV were described in 1983. From that beginning, the global epidemic of HIV has had a deep impact on the health of children and their survival. At least all the infections of HIV among young children are due to vertical transmission, which can occur in utero, intrapartum (through exposure to maternal blood products or transfusions), or post-partum through breastfeeding. Detection during the inter-partum period with more sophisticated

screening and diagnostic tests provides a crucial opportunity for prevention. Transmission after childbirth through the mother contributes about a third to half of the world's vertical transmission, which can be prevented with timely maternal treatment with retrovirals. In the absence of maternal antiretroviral treatment, the risk of HIV infection amongst infants is approximately 25% (ranging from 10% in European studies to 45% in African studies), but can go down to 4 to 8 % with maternal and infant antiretroviral treatment. Carefully designed studies of the epidemic are clarifying immunological, virological, genetic, and behavioral factors that affect the risk of transmission of HIV from the mother to the infant as well as response to antiretrovirals, and the natural history of the HIV infection in pre-natally infected children (1). One major advance in pediatric AIDS, however, has been the dramatic decrease in the number of new cases under the age of 13 (from 952 in 1992 to 50 in 2003) as well as the decrease in mortality from HIV/ AIDS in both the under 13 and 14-24 years of age groups in the United States. This has been the result of peri-natal maternal testing and of more effective antiretroviral therapies (4).

A major remaining challenge is the translation of these advances to poorer underserved populations and Third World regions of the world. One geographic area that has not received much attention related to the HIV/ AIDS epidemic is Latin America. Given its proximity to the United States and its contribution to immigration, particularly of young immigrants, it merits much closer attention. The Pan American Health Organization reports that today there is probably a higher rate of HIV infection in Latin America than in the United States. As of 1997, approximately 470,000 people have died of AIDS in the hemisphere, with 90,000 orphans resulting in Latin America alone, but these figures are considered under-estimates. Among the

812,000 cases reported in the hemisphere, all but 14,000 they are pediatric cases. Among the 22.6 million people that are considered living worldwide with HIV/ AIDS, 1.6 millions live in the Latin American and Caribbean region. Unless prevention programs are re-focused on these groups affected, the HIV virus could become the main cause of death amongst youths in Latin America and the Caribbean (9). Providing care to these populations, or to patients and their families in these countries, is an enormous task given the limited resources of developing nations. Additionally, the lower socio-economic status of women and children substantially limits the effectiveness of programs for care and prevention in developing nations (6).

Neurocognitive Aspects of HIV/ AIDS in Children

Among children, HIV penetrates early into the central nervous system (CNS) during the course of the illness. Abnormalities of the CNS are significant and frequent complications of AIDS in infants and children. Although their causes can be related to the HIV infection, malnutrition and poor pre-natal and post-natal care can also contribute significantly to such problems. Other factors that affect the neuropsychological function of seropositive children include prenatal insults, other diseases (such as other infections, strokes and neoplasms). (2)

Neurocognitive deterioration appears to be associated with the increased replication of the VIH virus, resulting in HIV-associated progressive encephalopathy (HIV-PE). HIV-PE is associated with a triad of symptoms: impaired brain growth, progressive motor dysfunction, and loss or plateauing of developmental milestones. HIV-PE has an estimated prevalence of 13 to 23 % amongst infected children. The course of HIV-PE in infants or young children is determined by its timing in the child's brain development, the strain of HIV, and genetic vulnerabilities. Three patterns of abnormal neurocognitive development have been described with HIV-PE:

rapid HIV-PE with loss of attained milestones, sub-acute progression of encephalopathy with relatively stable periods, and static encephalopathy with failure to achieve new milestones. Longitudinal assessments allow the differentiation between HIV-PE and mental retardation resulting from other factors, such as maternal drug addiction and poor pre-natal care. There is no obvious correlation between immunological status and the development of HIV-PE (7, 8).

Autopsy studies on patients with HIV PE reveal decreased brain weight, inflammatory changes, calcifications of basal ganglia vessels, white matter deterioration, and astrocytosis (8). Proposed mechanisms for the pathogenesis of HIV disease in the CNS include direct neuronal injury, macrophage destruction resulting in neurotoxicity, dysfunction caused by viral products, neuroreceptor blockade, co-infection with other agents, autoimmune reactions, antibody-mediated cellular toxicity, integration of the provirus in central nervous system cell lines, alteration of the blood-brain barrier, and brain vascular changes (7, 8). A high frequency of vascular lesions ranging from aneurysms to infarctions have been found using neuroimaging studies (9). The overall computerized tomography (CT) brain scan severity rating and the level of the neurotoxin quinolinic acid in the cerebrospinal fluid have been found to be highly predictive of the level of cognitive functioning and impairment in children (10).

Amongst children, the deterioration of language skills commonly occurs with HIV infections, particularly expressive more than receptive language. The periodic evaluation of language development should be part of the regular monitoring of infants and children with HIV infection as a method of evaluating the progression of the illness and the effectiveness of prescribed treatment. Visual-motor skills are another cognitive area sensitive in relation to the stage of the illness, method of transmission, and the environment that the child lives in (7).

Learning disabilities associated with cognitive impairment can be seen in elementary-school age children infected with HIV, which can be associated with gradual diminution in their mental function due to the disruption of cortical and/or sub-cortical structures (11).

The use of the retroviral medications can moderate some of the functional difficulties faced by these children and improve cognitive deficits, at least for a period of time. There is greater efficacy of retroviral treatment associated with greater brain impairment before treatment and better CNS penetration of the antiretroviral agent. However, the effect of retroviral treatment has not sustained been in many children beyond 6 months of treatment, with cognitive decline in the face of virological and immunological improvement, though recent advances have been made in this area. Specific neuropathological and neuropsychological defects are probably permanent, and there are limitations posed by the mechanisms of action of retroviral treatment (resulting in mutations and viral resistance) as well as interactions amongst multiple drugs used in treatment (2, 12,13).

Psychological Impact of Pediatric AIDS

HIV infection and AIDS have a very significant psychosocial impact on patients, their families, and society in general, including psychological, cognitive, emotional, and social effects. This illness in children has important and durable effects on their families. Additionally, most families affected by the HIV are of minority and disadvantaged backgrounds, and are already discriminated and stigmatized in the society. AIDS affects many children and adolescents with parents who are also victims of the disease themselves. There are thousands of children with fathers who are close to death or already dead, and thousands with mothers who have died from AIDS or are too ill to serve their role of primary parent or caregiver. Even when

the parents live, psychological pressures on the parents, the use of drugs, and their sexual lifestyles are parts of the conflicts between parents infected with HIV and their adolescents (2, 14, 15).

In the year 2000, approximately 100,000 children less than 18 years of age lost their mothers to AIDS. Approximately one-third of these children live with a father who is HIV positive, one-third with a grandmother, and one-third in an orphanage or adoptive care. Most of the caretakers for children with HIV are single mothers that face the biggest challenges in their lives alone, and are over-extended with the responsibility of caregiving. Those families are primarily African-American and Latino of low socioeconomic levels and of limited economic resources. The children have been sensitized to loss and anticipated separation, and their caretakers feel a great burden of anguish and anticipatory grief. The caretakers of these children need to be aware of the problems of children infected with HIV. The physical and psychological care of these children and infected adolescents are a major challenge, and it affects the whole family system (14, 16). At the other end of the spectrum, the transition from adolescence to adulthood and to greater self-sufficiency also present significant challenges to HIV infected youth. Youth need to address a number of adaptations, ranging from greater demands for self-management of their health care, the impact of their illness on their emerging sexuality and independence, and the often difficult transition from familiar pediatric health care settings to unfamiliar adult providers (3).

There is great psychological impact on the increasing numbers of adolescents and children acquiring the HIV infection and developing AIDS from the medical and psychosocial consequences of the illness. Many of them have lost parents, other relatives, and friends to

AIDS, leading to a double psychological impact. These children are beneficiaries of the greater openness around the diagnosis of HIV and AIDS, but there are many other cultural and social conditions that complicate their future adaptation. The stigmatizing public response, with fear of contagion, association with drugs and homosexuality, and anxiety about the threat of contracting the disease, leads to feelings of isolation and rejection (2).

Children and adolescents with HIV/AIDS experience more subjective distress than their uninfected peers, including dysphoria from the physiological effects of the illness, hopelessness, preoccupation with their illness, and poor body image. Facing and understanding their own possible death are major challenges faced by children and youth with HIV. The cognitive and emotional maturity of the child often determines their level of awareness about their own mortality, as well as their coping skills and defenses to deal with this realization. Children's reactions can range from unawareness of the finality of death in very young children, to increasing awareness and anxiety in the elementary age period, to major existential conflicts in teenagers. Negative and traumatic life events such as forced disclosure about their illness, a history of abuse (physical or sexual), and loss of a parent or sibling contribute to heightened distress. Coping with HIV infection may trigger many emotional responses, including social withdrawal, loneliness, anger, confusion, fear, numbness, and guilt. Various adaptive cognitive approaches and coping styles are used by HIV infected children and youth, including denial, reaction formation, resignation, self-calming, distraction. Some adolescent with HIV/AIDS report more sexual risk-taking behaviors and conduct and hyperactivity disorders, at times driven by their underlying distress. Also contributing to the level of experienced distress is the cultural context within which HIV/AIDS is experienced by the child or adolescent. People of different

racial/ ethnic and socioeconomic backgrounds cope with HIV/AIDS in different ways, according to their social mores and cultural traditions, thus experiencing varying levels of stigma, shame, or social support. The success or failure of these coping reactions or strategies not only influence the level of emotional distress experienced by children with HIV/AIDS, but also the distress they experience from pain, and their demands for pain relief (2, 17,19).

Children with HIV suffer of a wide spectrum of psychiatric manifestations that extend from depression to anxiety to behavioral disturbances. Amongst adults with HIV/AIDS, lifetime rates depression range from 32 to 56 %, and suicidality is common amongst homosexual and bisexual men. In one study of 34 HIV-positive adolescents using structured diagnostic interviews, 44% presented with current major depression, 85% had at least one DSM diagnosis, and 53% had a history of psychiatric disorders prior to HIV infection. Another study comparing children with HIV infection with children with asthma showed that anxiety disorders were more common in the HIV-infected group than in the asthma group. Children that suffer of depression are isolated and fear an early and unavoidable death. They also suffer anxiety accompanied by the fear of transmission, and feel guilty to be a burden to their family (2, 19, 20).

The brothers and sisters of children suffering with HIV experience numerous emotional difficulties. Frequently, those not affected by the illness report anger because they have to assist their brother/ sister with the illness. Many of the brothers and sisters feel guilty to not be the one affected, and they feel isolated and fearful of contracting the illness. The fear of contracting the illness by the non-affected sibling is influenced by numerous factors such as their age, level of education, knowledge of and understanding about the illness, and attitudes about the illness (2).

Intervention and Psychological and Psychiatric Treatment

The family with children with HIV is generally a family dealing with crisis, illness, lack of resources, and social isolation, and in need of support and medical, psychological and social services. There is also a high frequency of co-morbid drug abuse and mental disorders in HIV-infected parents. It is important to assist these children and their families through interdisciplinary interventions oriented to improving the child and family's quality of life. Family-centered approaches have been advocated that address family stresses, adaptation, and cultural factors impacting on the whole family. They also provide developmentally-appropriate supports for the infected child and his/her siblings, and connect families to services and community resources and supports (including medical, mental health, social welfare services, and such critical services as respite care), through case management (2, 21, 22).

Comprehensive psychiatric, psychological, and neuropsychological assessments are critical components in the overall care for children and youth with HIV. Psychiatric evaluation is important in assessing the presence of depressive, anxiety, and psychotic symptoms (such as hallucinations) related to the psychological impact of the illness on the child and/or the effects of retroviral treatment. Mental status evaluation is important in determining the presence of any symptoms of attentional deficits, memory impairment, or even full-blown dementia in advanced cases. Psychological and neuropsychological testing is important in providing objective assessment of cognitive and developmental progress. These include the Weschler Intellectual Scales for Children (4th Edition) and the in older children and youth, and the Bailey Scales of Development, the Vineland, and in younger children. Neurological examination is important to detect the presence of such signs as abnormal reflexes,

bradrykinesis, and spasticity. Neuroimaging tests are also important in such comprehensive evaluations when more advanced neuropsychiatric complications are suspected.

Electroencephalography (EEG) is important whenever there is any suspicion of seizure activity or focal neurological findings. Computerized tomography (CT) of the head can be used to evaluate structural changes associated with neuropsychiatric complications, such as microcalcifications (especially in the basal ganglia), and brain atrophy with increased ventricular size and increased cerebral sulci. Magnetic resonance imaging (MRI) of the head can be used to evaluate cerebrovascular findings, such as signs of ischemic strokes and cerebral artery aneurysms, and the presence of mass lesions from toxoplasmosis or central nervous system lymphoma. Positron emission tomography (PET) findings have demonstrated diffuse hypermetabolism, though these are experimental in nature (Refs here.....).

Therapeutic support has the greatest role in the care of the children with HIV. Supportive and cognitive therapy for these children and their parents and families is essential because these they are most vulnerable to separation and loss. Support groups and structured programs for HIV infected youth have demonstrated effectiveness. The use of active strategies within these groups, such as problem-solving and help-seeking, have been shown to be helpful, though these are more consistent with Western cultural orientations. Two important areas of focus in support groups are those of disclosure of HIV infection and adherence with treatment, with failure of disclosure out of fear of social stigma often leading to poor treatment adherence. Improving adherence with HIV treatment regimen and approaches to disclosure of HIV status can also be the target of psychosocial and support group interventions, with youth sharing effective strategies for addressing both challenges (2, 3, 23).

Safe sex interventions have been developed for HIV infected youth to enhance the use of condoms, build social skills, improve self-efficacy, and create supportive peer norms. These interventions target the cognitive immaturity and exploratory learning behaviors commonly seen in adolescents, as well as other factors such as impulsivity, distress, and adverse life experiences. Both psychotherapeutic and psychoeducational approaches have been shown to be effective in reducing risky sexual behaviors. For example, a study by Brown and colleagues studied a 12-month motivational skills intervention with 111 adolescents living with hemophilia and HIV, and demonstrated significant increases in condom use, safer sexual practices, and increased self-efficacy (3).

The care of the children infected with HIV is very difficult and affects the whole family system. Psychological supportive therapy for the family and caregivers of the infected children is an area of mental health services in very high demand and need. These services help to reduce isolation, promote family function, and teach coping skills and abilities (14).

The most frequent psychodynamic themes for children infected with HIV involve their guilt, self-esteem, and matters related to death. Mental health professionals can help the child to face his/her guilt feelings, feelings of being punished, depression, and fears of death. Both individual and group therapies are effective. Individual therapy could be brief or long-term and could be supportive, cognitive, behavioral, or psychodynamic in focus. It is very important to form a strong alliance with the family in the treatment of children with HIV. The parents and family of children with HIV feel extremely guilty about the transmission of the illness (19).

Psychopharmacological treatment of seropositive children and adolescents with HIV is the subject of a lot of debate. A versed balance of risks versus benefits in the use of

pharmacotherapy needs to be determined for each individual case. The hyperactivity associated with HIV encephalopathy in children has been treated with methylphenidate and with clonidine, with good results. Although psychotherapy should be used in the treatment of anxiety in patients with HIV/ AIDS, the use of drugs anxiolytics could be necessary. It is preferred to use an anxiolytic with a short-acting pharmacokinetics rather than longer-acting ones. Many experts believe that depression in patients infected with the AIDS should be treated aggressively with antidepressant medications. Serotonin reuptake-inhibitor antidepressants have been used with very good results in older patients with AIDS, since tricyclic antidepressants can worsen the confusion associated with HIV encephalopathy (2, 24).

With children, it is especially important to begin with a small dose and then increase it slowly until the therapeutic effect and dose are reached. It is also important to be aware of drug-drug interactions between psychiatric and neurological medications (such as the sedative hypnotics, amphetamines, anticonvulsants, and some antidepressants) and some retrovirals, either through direct interactions or the inhibition of hepatic metabolism. These may result in the child or adolescent with HIV/ AIDS not being able to use some psychiatric medications (such as the sedative hypnotics and amphetamines) or requiring lower doses (such as carbamazepine and bupropion; 2).

Conclusions and Future Directions

The scientific advances in the medical treatment of HIV/ AIDS have been highly significant over the past 10 years, and these promise to improve the longevity and quality of life for children and youth infected with HIV. Additionally, pre-natal testing and community preventive approaches targeting safe sex and intravenous drug abuse should also contribute to a

stemming and reduction in this dreaded disease amongst children and youth. However, the context of HIV/ AIDS within poverty, minority status, and disenfranchised and underserved populations (not only in the United States but worldwide) presents significant barriers to the application of these scientific advances. Effective approaches and models that address the psychosocial, cultural and systemic context of this epidemic will prove to be as important if not more important than the biological advances in diagnosis and treatment (24).

Since pediatric HIV and AIDS impacts the child and family and community at so many levels, there is a significant parallel with the multi-level impact of serious emotional disturbances on children and families. There may be significant value in the adaptation of systems of care approaches developed in the child mental health arena for serious emotional disturbances. These approaches have promoted interdisciplinary and inter-agency collaboration, services that are culturally competent and delivered within the child's own community, individualized care that is driven by and empowers children/ youth and families, and the use of community supports and the reduction of stigma. These approaches have been demonstrated to be particularly successful in delivering mental health services for disenfranchised, underserved populations, similar to those amongst whom HIV/ AIDS is most rapidly increasing (25).

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