Occupational Therapy for Children With Perinatal HIV Infection

Jill Anderson, Jim Hinojosa, Gary Bedell, Margaret T. Kaplan

Key Words: child development • occupational therapy services

This article discusses occupational therapy for children with perinatal HIV infection and their caregivers. An interdisciplinary early intervention and preschool program serving these children is described. Current medical and neurological research is reviewed to serve as a basis for occupational therapy intervention. Therapeutic approaches that integrate physical, neurological, developmental, and psychosocial needs are presented.

AIDS, with its toll on human life and the suffering it causes, is a major health crisis. Children with HIV infection have been reported in 29 states; 72% of pediatric cases reported are in Florida, New Jersey, and New York (Quinn, 1987). Koop (1987) reported that according to the U.S. Public Health Service, 3,000 children will have contracted the disease and died by 1991. Further, Kastner and Friedman (1988) maintain that by 1991 AIDS will occur in between 1 in 750 and 1 in 1,500 live births. This would approximate the current incidence of Down syndrome and meningomyelocele in the general population.

As the number of children with AIDS or HIV infection rises, the chance that a therapist will treat such a child is increased. Occupational therapists practicing in neonatal intensive care units, early intervention programs, school systems, or programs designed specifically to serve children with HIV may be treating this population. Therapists may be working unknowingly with an isolated child with AIDS or HIV infection. Currently, most children with HIV are from families with a history of intravenous drug use. The number of infected children in the general population is expected to increase as the virus spreads.

The clinical picture of the symptomatic HIV-infected child can include medical, neurological, physical, cognitive, and psychosocial deficits. Varying degrees of severity contribute to a complex clinical picture often accompanied by developmental delays (Ultmann et al., 1987). Occupational therapy treatment of these children can involve several different treatment approaches as well as interdisciplinary efforts.

Literature Review

Denton (1987) focused on occupational therapy assessment and treatment of adults with AIDS, and Schindler (1988) offered a psychosocial treatment perspective. Although some of the psychosocial and family issues may be similar for adults and children with AIDS, the evaluation and treatment of neurological and developmental dysfunction will differ. Progressive neurological disorders may be more serious in the pediatric population, including developmental delays, increased reports of perceptual motor dysfunction, encephalopathies, and seizure disorders (Dekker, 1988).

The Centers for Disease Control has developed a classification system for HIV infection in children under 13 years of age based on a continuum of symptomatology, from asymptomatic to symptomatic (U.S. Public Health Service, 1987). The symptomatic child has two or more commonly observed immune abnormalities associated with HIV infection.
Currently, many of the children with HIV are expected to become more symptomatic and to die of complications from the disease (Quinn, 1987). This prognosis, however, may change with increased understanding of the disease process and future medical advances. At the National Institutes of Health, the preliminary results of research on the use of azidothymidine (AZT) with children are encouraging (Kolata, 1988).

The HIV virus is transmitted by the direct exchange of body fluids, predominantly semen and blood. Prenatally, this may occur when blood is exchanged through the placenta. Minkoff, Nanda, Menez, and Fikrig (1987) suggested that the virus may also be transmitted during the birth process. Transmission of the infection through casual contact or among family members living in the same household is unlikely unless they engage in unsafe sexual contact or share needles. Additionally, three cases of HIV being transmitted to newborn infants through breast milk have been reported (Lifson, 1988).

Most cases of HIV infection in children result from prenatal or perinatal transmission from the mother. According to Guinan and Hardy (1987), women account for 6.7% of all AIDS cases; 79% of these women are between the ages of 13 and 29 years. Wofsy (1987) reported that 80% of pediatric AIDS cases were traced to infected mothers. Dekker (1988) summarized the distribution of pediatric AIDS cases by transmission categories: 46.3% resulted from the mother's use of intravenous drugs; 14% from blood transfusions to the baby; 12.3% from mothers born in a country outside of the United States (the prevalence of AIDS is much higher in women in some other areas of the world); 10.9% from mothers whose sexual partner was an intravenous drug user; and 16.5% from unreported sources. Currently, most pediatric AIDS cases are associated with parental use of intravenous drugs.

Infants who test positive for HIV antibodies at birth may or may not be HIV-infected. Tests taken during the infant's first few months of life measure antibodies to the HIV virus in the blood. Current tests cannot yet distinguish the mother's antibodies from those produced by the child in response to infection. When the child's immune system becomes more developed, the mother's antibodies disappear and the child may then test negative for the presence of antibodies. This process is thought to occur between 9 and 15 months of age (Mendez, 1988). Children up to 15 months of age should be monitored and tested regularly for the persistence of HIV antibodies, which would indicate the presence of the virus rather than the presence of the mother's antibodies in the infant's bloodstream (U.S. Public Health Service, 1987).

Klug (1986) reported that some children may have the following dysmorphic features associated with perinatal infection: microcephaly; hypertelorism; a prominent, boxlike forehead; a flattened nasal bridge; or a mild obliquity of the eyes. A study by Qazi, Sheikh, Fikrig, and Menikoff (1988) did not support the existence of craniofacial features and other anomalies in children exposed to perinatal HIV infection.

### Neurological Deficits

Epstein et al. (1986) determined that during the prenatal or perinatal period, the incubation period from initial HIV infection to progressive encephalopathy varies from 2 months to 5 years. A child who is born with or who acquires symptomatology in early infancy is suspected to have been infected in an early stage of fetal development (Epstein et al., 1986).

According to Epstein et al. (1986), 50% of children with HIV infection develop progressive encephalopathy, the characteristics of which are impaired brain growth, loss of developmental milestones, and progressive motor dysfunction with pyramidal tract dysfunction. Delays in the acquisition of motor milestones and the development of perceptual motor abilities and expressive language also occur. Epstein et al. (1986) support the hypothesis that progressive encephalopathy in children with HIV is caused by primary infection of the brain. The signs of progressive encephalopathy indicate a poor prognosis and almost always death.

Rubinstein (1988) hypothesized that the virus may directly enter the central nervous system, causing neurological deficits. Opportunistic infections and lymphocytes and monocytes produced secondarily may enter the central nervous system and may also contribute to deficits. All of these factors may hinder the myelination process, thereby contributing to motor and other developmental problems.

Belman et al. (1985) reported case studies of 6 HIV-infected children with neurological dysfunction, aged 6 months to 6 years. The most consistent neurological manifestations were encephalopathy; acquired microcephaly; pyramidal tract dysfunction, varying from hypotonia to hypertonia; and seizure disorders. Three children developed dementia, and 2 children developed progressive apathy with a deterioration of play skills and a total loss of interest in the environment.

In a later study, Belman et al. (1988) reported on 51 of 60 HIV-infected children. These children had developmental delays in gross motor, fine motor, and language skills, and most of them had cognitive impairments ranging from profound to severe. Motor impairments included mild to moderate spastic diparesis, spastic paraparesis, spastic quadripareisis and hemiparesis, and generalized hypotonia. As their ill-
nesses advanced, 4 children developed rigidity, 1 developed dystonic posturing, 6 developed ataxia, and 3 developed tremors.

Ultmann et al. (1987) studied 16 children aged 6 months to 6 years. Regression in developmental milestones was consistent with deterioration in their neurological status. Cognitive and neurological impairment was documented in all but 1 child. Several children showed a discrepancy between neurological and developmental findings, and some showed neurological signs without developmental regression.

The clinical picture of the HIV-infected child may also be complicated by prematurity and low birth weight (Minkoff et al., 1987). Ultmann et al. (1985) reported that 5 of 14 children who tested positive for HIV were born preterm and one was small for gestational age. In addition, 2 of the full-term children were small for gestational age. Prematurity and low birth weight have been associated with adverse developmental outcomes and must be considered in the assessment of developmental findings. Prenatal use of drugs affecting the developing fetus also was evident in the sample.

Psychosocial Development

Children with HIV infection may be affected psychologically by repeated hospitalizations, separation from caregivers, and isolation stemming from infectious disease precautions. Erratic caretaking and a stressful home environment may also affect the child's social-emotional status (Ultmann et al., 1985). Additionally, the social environment most likely has a negative effect on those children born to parents who use intravenous drugs (Kastner & Friedman, 1988). The family structure may be further affected by the death or illness of either or both parents.

Families may be stigmatized by societal reaction. According to Klug (1986), "Parents are faced with social isolation, a financial burden, a sense of loss of control, and a lack of confidence in their parenting ability" (p. 1131). Parents may have to deal with guilt about their child's illness. Further, these parents' views of themselves and their child may be affected by society's prejudices.

Precautions Related to HIV Infection

The postnatal period of the child with HIV infection may be complicated by such conditions as recurrent upper respiratory tract infections, otitis media, thrush, erythematous rash, lymphadenopathy, and cytomegalovirus (Cowan et al., 1984). Working with children with cytomegalovirus or toxoplasmosis may be contraindicated for pregnant therapists due to a risk of adverse effects on the developing fetus. Klug (1986) outlined some basic caretaking principles: (a) avoid exposing the child to common infectious diseases of childhood, (b) wash your hands after every contact with the child's secretions (e.g., after feeding and toileting), (c) encourage caregivers to wear gloves when changing diapers or handling blood or blood by-products, (d) be aware that immunization for the child with AIDS may be contraindicated, and (e) do not expose the child with AIDS to recently vaccinated children for the period of infectivity that follows a live vaccination. When working with parents, health care professionals should be concerned with living conditions while also addressing (a) physical care, (b) how to prevent the spread of infection, and (c) how to control opportunistic infections (Klug, 1986).

Professional Issues

Fear of contagion and issues related to working with terminally ill patients may cause the therapist anxiety about working with children with HIV infection. Some professionals may not be comfortable with current knowledge about the process of transmission. Fear and uneasiness for the safety of oneself and one's family may persist. Furthermore, the negative reactions and fears of family members, friends, and caregivers may influence the therapist's feelings about contact with AIDS patients. Increased knowledge and understanding of the etiology of the disease and its sequelae may lessen such anxiety.

Not all therapists are able to work with terminally ill patients. Therapists' reactions may be compounded by their own feelings of attachment and reactions to loss. These feelings may be especially poignant when therapists work with young children.

The background of the population at risk may raise personal questions for individual therapists. Some therapists may be uncomfortable working with children of parents who might be prostitutes, intravenous drug users, or bisexuals. These therapists may benefit from supervision or professional support to help them deal with their feelings and values.

The Occupational Therapist's Role

Historically, occupational therapists have responded to the unique needs of the chronic and progressively disabled patient. They have developed specific treatment strategies to enhance the quality of life for patients with such infectious diseases as leprosy, poliomyelitis, and tuberculosis. They have also worked with terminally ill patients and in hospice settings (Folts, Tigges, & Weisman, 1986; Pizzi, 1984). In many respects, occupational therapy interventions for children with HIV infection are similar to those used with developmentally disabled and chronically and terminally ill children. As stated by Denton (1987),
The disabilities that result from AIDS do not require a change in occupational therapy intervention approaches. Therapists working with AIDS patients may be more effective if they use the ‘whole person’ concept to address the psychosocial, physical, and environmental factors influencing function. (p. 429)

Intervention: An Integrated Approach to Treatment

The Infant and Child Learning Center of the State University of New York, Research Foundation, Health Science Center at Brooklyn, is an interdisciplinary early intervention and preschool program serving children who are at risk for or already demonstrating developmental delays. The majority of children treated are under 3 years of age; all of the children are under 5 years of age. The component of the program serving children with HIV infection was developed in response to the increasing numbers of these children seen in hospital clinics. In addition to medical problems, these children exhibit a variety of developmental delays. An interdisciplinary program including education, occupational therapy, physical therapy, speech therapy, psychology, social service, and pediatric nursing was established.

Children attend this program with their parent or caregiver for half-day sessions three times a week. Services are provided within an educational framework on the basis of each child’s needs. Caregivers can attend a weekly support group led by a social worker and a psychologist. Therapists and teachers also provide inpatient services if a child is hospitalized at either the State University Hospital or Kings County Hospital Center, Brooklyn, New York. The program for children with HIV infection provides daily medical screening by a pediatric nurse and ensures immediate medical attention. Further, the program offers a support network to caregivers and children who have experienced social or community isolation or who are afraid of incurring this isolation should their situation become known.

General occupational therapy goals for all the children in the program are to increase play and social skills, develop self-care skills, improve self-concept, facilitate cognitive-perceptual development, and facilitate motor development. Treatment priorities vary and are sensitive to each child’s medical, physical, and psychosocial needs.

The program addresses the needs of the child, the caregiver, and the professionals. When working with the child and the caregiver, the therapist adopts an attitude of unconditional positive regard as the basis for psychosocial intervention (Rogers, 1961). This is an attitude of nonjudgmental acceptance of the child and caregiver and of their life situation.

Evaluation

The evaluation process involves in depth observation of sensory responses, gross and fine motor skills, cognitive and adaptive skills, play, and socialization. An interview with the caregiver provides additional insight into the child’s play history and behavior and the caregiver’s specific concerns about managing the child’s needs.

A criterion-referenced assessment based on developmental tasks and neurodevelopmental behaviors is recommended for evaluation of the child. Each facility will have its own assessment. As long as it assesses the behaviors described, the specific tool is unimportant. This type of assessment was selected because it was considered to be most relevant in the planning and implementation of treatment. Special considerations when one is evaluating children with HIV infection are fatigue, pain, frustration, irritability, depression, and separation anxiety. Separation anxiety may be more intense because of frequent hospitalizations, medical appointments, and unstable family environments.

The assessment is further complicated because these children have higher instances of opportunistic infections, decreased respiratory capacity, fever, diarrhea, and dehydration. Tactile and movement sensitivity, which have been observed frequently in these children, may necessitate additional assessment and special consideration.

Standardized tools (e.g., Movement Assessment of Infants [Chandler, Andrews, & Swanson, 1980], Peabody Developmental Motor Scales [Folio & Fowell, 1983], Miller Assessment for Preschoolers [Miller, 1982]) may be used when specific information is needed in one area of development or function. Standardized tools may also be used when research data are being collected. Due to the progressive nature of the disease, reevaluations may be more frequent.

When writing evaluation summaries at the Infant and Child Learning Center, therapists are careful not to include the diagnosis of HIV infection or its identifying characteristics. Special attention is taken to describe the child’s specific developmental dysfunctions. Such precautions are important for reasons of confidentiality, anonymity, and avoidance of potential discrimination toward the child and his or her caregivers. Additionally, reimbursement may be affected by a diagnosis of HIV infection.

Intervention

Treatment priorities for the child with HIV infection must be flexible in response to the child’s changing...
Medical and psychosocial status. Many children are well for several years but become sick periodically. Special attention is given to children reentering the program after illness. Children returning from prolonged hospitalization or home convalescence often display increased fear, distrust, and apathy. Therapeutic relationships must be periodically reestablished or strengthened. The child may need extra time to separate from the primary caregiver. The child may also require additional time to participate in group activities. During this reentry process, collaboration between the therapist and the caregiver is essential.

For the purposes of this article, intervention concepts are presented in categories based on areas of dysfunction observed in children with HIV infection. During treatment sessions, approaches that combine physical, neurological, developmental, and psychosocial objectives are integrated.

Psychosocial intervention. Psychosocial needs are responded to in several ways. When the child is physically ill or distressed, psychosocial needs become the major focus of intervention. Occupational therapists are concerned with maximizing environmental interactions that are pleasurable to the child, such as playing with desired toys. These interactions also increase the child’s opportunities to engage in a variety of play activities and socialization experiences. The encouragement of movement for enjoyment, such as playing basketball or crawling through a tunnel, may be more important than the elicitation of normal patterns of movement. Activities promoting both, however, can often be achieved.

Sensorimotor intervention. Principles of neurodevelopmental treatment and sensory integration form the theoretical basis of the approach used for the treatment of sensorimotor deficits. Many of the children in the program have abnormal muscle tone and movement patterns as well as delayed development of righting and equilibrium reactions.

Some children exhibit muscle tone that resembles spasticity or rigidity, which is often apparent soon after birth. Other children appear to have low tone and decreased postural stability, but when moving against gravity, they may develop tightness, or tone may increase in an effort to maintain stability. Abnormal movement patterns may eventually contribute to contractures or deformities.

Some children do not exhibit abnormal tone or weakness but have delayed sensorimotor development. Increased illness, hospitalizations, and sometimes overprotection from parents may limit sensory and movement experience as well as motivation.

Some children with HIV infection have movement and tactile sensitivity. They tend to avoid sensorimotor experiences and respond negatively to tactile input and movement experiences. Although the reason for the movement and tactile sensitivity is not known, we suspect three contributing factors. First, some caregivers overprotect their children and tend to carry them rather than encourage them to move. Second, many of these children have limited sensorimotor and play experiences secondary to hospitalization and medical management restrictions. Finally, these responses may be indicative of the effects of the disease or other perinatal factors on the central nervous system.

Biomechanical and kinesiological principles are used to design and fabricate splints and appropriate adaptive and positioning equipment. These devices require constant reevaluation for effectiveness in response to the dynamic disease process.

In summary, sensorimotor functioning may deteriorate at varying rates for individual children. Medical advances, however, may improve the clinical picture of the sensorimotor development of these children.

Cognitive intervention. Cognitive levels vary considerably in children with HIV infection. Some children are severely cognitively impaired from birth. Cognitive deficits may also occur from viral infection affecting the central nervous system and from environmental deprivation. In many children, cognitive deterioration with age is evident during play and learning activities. In some cases, the child’s cognitive abilities do not keep up with age expectations and new skills do not develop.

Cognitive deficits are treated during therapy through play activities that may involve matching, ordering, sequencing, and classifying. Other cognitive skills such as the ability to attend, follow directions, and problem-solve, are also addressed in treatment.

Many children seen in the Infant and Child Learning Center have delayed language acquisition. A limited vocabulary, less frequent vocalization, and difficulty with the initiation of speech is also observed. Bilingual family backgrounds, lack of stimulation, possible central nervous system involvement, and the effects of hospitalization may produce these delays.

Perceptual-motor intervention. Fine motor delays have been observed in many children with HIV infection. Children with increased muscle tone tend to have immature or abnormal prehension and reaching patterns.

Deficits in eye-hand coordination and other visual-perceptual skills are often seen in these children. For example, during the administration of the Peabody Developmental Motor Scale, a 3-year-old child with HIV infection having normal prehension of 1-in. cubes was unable to successfully stack them. He appeared to have difficulty with visually directed grasp.
and the integration of visual-perceptual information. Further investigation of prehensile patterns and visual-perceptual skills in children with HIV infection is indicated.

**Self-care intervention.** Feeding is important to maintain optimum health and nutrition. Due to frequent infections and illnesses, some children may stop eating, thereby further endangering their health. Children with HIV infection often have frequent episodes of rapid-onset pneumonia, which interferes with their appetite and feeding. They may also have sores or infections (e.g., thrush) that affect feeding. In such cases, the child is offered bland, smooth, or pureed food until the infection subsides. Occupational therapy may also focus on other related feeding problems. Abnormal oral motor patterns may require intervention to improve feeding. Positioning and handling may be required to normalize postural tone while feeding. Adaptive equipment is sometimes recommended.

**Working with caregivers.** Working with the primary caregiver is inherently complex. The family configuration is complicated by parents who have died or who are ill, by extended families, or by foster parents. Further, the effects of some behaviors of family members (e.g., drug use) may continue to influence the stability of the family. The primary caregivers may also be experiencing their own losses, possibly related to their health, the death of a loved one, or concerns about the child with HIV infection.

A major focus of occupational therapy intervention is to enhance the caregiver-child interaction. The therapist must increase the caregivers' awareness of the child's strengths and special needs as well as suggest specific activities. For example, after the death of one child's mother, the grandmother became the primary caregiver. Although she appeared to have a somewhat fatalistic attitude about the child's future, she also tended to pamper and overprotect the child. She felt that the child would not be happy playing with the other children in the program, which she confirmed through the child's crying and inconsolable behavior. She also appeared to be embarrassed by the child's behavior. Working closely with the grandmother, the teacher and therapists reinforced the child's strengths and need for time to adjust and feel comfortable. Gradually, the grandmother began to view the program and the child more positively.

Several caregivers were initially fearful of moving or playing with their children with HIV infection. The therapist encouraged these caregivers to observe or participate in treatment and explained the sensorimotor effects of the movement activities, which seemed to alleviate much anxiety. The staff observed a gradual improvement in the quality of the interactions between the child and the caregiver in all cases.

**Staff support system.** Due to the progressive and terminal nature of HIV infection, staff need a formal or informal support network. Staff in the Infant and Child Learning Center currently use informal support mechanisms. These networks provide opportunities to discuss feelings about specific children and their caregivers, such as observation of progressive symptomatology in a child, as well as feelings about a parent's illness or death or about a child's death. For example, when a child who had been in the program for a year died, the staff met to discuss how they would present the child's death to the other children and their caregivers. Additionally, the social worker held a formal group meeting for the staff to deal with their feelings of loss.

**Conclusion**

The goal of occupational therapy for children with HIV infection is to offer opportunities to improve the quality of their lives, accept them with unconditional regard, and foster their development.

It is important for therapists to treat the child with HIV infection holistically and not just treat the child's discrete developmental delays or neurological signs. AIDS is a complex condition that develops differently in each child, thus making generalizations difficult.

Research is needed on many issues related to children with HIV infection. Occupational therapists, in particular, need to determine what areas they will study while continuing active treatment with these children. Specific areas of research may include assessment of the differences in abnormal movement and tone; identification and treatment of the psychosocial needs of children with HIV infection and their families; and the assessment of specific interventions. ▲

**References**


**Related Readings**
