Children with human immunodeficiency virus (HIV) infection can participate in all activities in school to the extent that their health permits. The ability of the school to educate these children will depend on the severity of the disease. HIV infection has a wide clinical spectrum ranging from the asymptomatic child to the child with progressive acquired immunodeficiency syndrome (AIDS) who is deteriorating clinically. The child who is HIV-seropositive but is asymptomatic in appearance and activity is indistinguishable from the well child. The education of this child should not differ from the education of other children. The child who develops symptomatic HIV infection, however, may have evidence of central nervous system dysfunction resulting in decreased cognitive function and poor academic performance. Behavioral problems due to the chronic illness and increasing family disruption may interfere further with education. Issues of confidentiality may limit communication with the school. These problems pose challenges to school personnel and pediatricians attempting to optimally serve children with HIV infection.

Children with HIV infection should not be excluded from school for the protection of other children or personnel, nor should they be isolated within the school setting. Exclusion of HIV-infected children from school to protect that child's health is not required in most instances, and such decisions should be made by the physician in consultation with the child's parent or care giver. (American Academy of Pediatrics. AIDS and Ethical Issues. Manuscript in preparation). Participation in school provides a sense of normality for the HIV-infected child and offers opportunities for socialization that are important to child development. School attendance also promotes a sense of belonging and reduces feelings of isolation and rejection. The pediatrician, acting as the child's advocate, should be familiar with those neurologic and behavioral aspects of HIV infection that are associated with educational impairment and should provide counseling to the family and school while maintaining appropriate confidentiality.

HIV INFECTION AND DEVELOPMENTAL DELAY

Children with symptomatic HIV infection may develop severe developmental disability including intellectual impairment. This may be a direct result of central nervous system infection with HIV, but other factors, such as perinatal drug exposure, malnutrition, and repeated infection, also can contribute. Recent studies have shown that 78% to 93% of children with symptomatic HIV infection show some developmental abnormality. Four characteristic courses have been described: (1) rapidly progressive central nervous system deterioration; (2) subacute, but steadily progressive central nervous system dysfunction; (3) a subacute course punctuated by periods of stability followed by deterioration; (4) a static course. Symptoms vary from a mild developmental delay to progressive disease with acquired microcephaly, developmental regression, spasticity, and growth failure. Even children who maintain a static course frequently show cognitive defects with visual-spatial and perceptual dysfunction.

As more children are born with this infection and survive for longer periods of time, there will be an increasing need for developmental assessments to plan educational programs. The Education for All Handicapped Children Act (Public Law 94-142) stated that all handicapped children aged 3 years and older are entitled to a free and appropriate education in the least restrictive environment. Infants and toddlers with HIV infection who have significant developmental delay or who are at risk for such delays are eligible for assistance under The Education For All Handicapped Children Amendments (Public Law 99-457) and may be eligible for
special services depending on state regulations. In some states, they may also be eligible for special services because they are at increased risk of developmental delay and potential learning problems. Thus, public school educational programs must be available for HIV-infected children from preschool through the school years. The pediatrician is responsible for initiating developmental testing and for referring children to appropriate early intervention and educational programs. The need for home instruction should be reviewed by the child’s physician. The child’s physician, to coordinate working with the school medical advisor or other physician to help determine educational planning. He or she can also help to plan educational programs for faculty, students, parents, the community, and the media about HIV infection and the educational needs of the HIV-infected child.

HIV AS A CHRONIC DISEASE

The child with symptomatic HIV infection should be regarded as a chronically health-impaired child. School personnel need to be oriented to the needs of the child with chronic disease. To benefit from education, children with HIV infection need to have health services available in their schools. Children who are capable should be allowed to self-administer medication while in school. Teachers, as well as nurses, should be trained in recognition and management of emergencies. School personnel should also be trained in routine procedures for handling of all blood and blood-containing body fluids. Homebound teaching should also be readily available, and school attendance policies need to be flexible. Physical education programs suitable for the needs of the developmentally disabled or chronically ill child should be developed. Depending upon their capabilities, children with progressive disease may require home instruction, occupational and physical therapy, or mental health services.

HOME INSTRUCTION

Due to intercurrent illness, children with symptomatic HIV infection may be absent from school frequently and may require home instruction until their condition improves. As the illness progresses, the child may need to be kept at home. Educational programs, including home teaching, should be provided promptly under the guidelines of Public Law 94-142 through the school special education coordinator working with the school medical advisor or the child’s physician. The child’s physician, together with the school nurse, should facilitate the transition between school and home instruction. The need for home instruction should be reviewed within the context and guidelines of the American Academy of Pediatrics Policy Statement on Home Instruction.

HEALTH-RELATED THERAPY

Children with symptomatic HIV infection may demonstrate visual-spatial and perceptual dysfunction. Neurologic findings, including poor fine motor coordination, clumsy rapid alternating movements, or abnormal gait\textsuperscript{6,7} have been demonstrated in 75%. Such children need occupational and/or physical therapy and speech/language help under appropriate medical supervision.

BEHAVIORAL ASPECTS

As in other chronic illnesses, children with symptomatic HIV infection frequently exhibit behavioral symptoms, such as anxiety, depression, anger, and withdrawal, that can interfere with educational efforts. These behavioral problems may be due to the neurodevelopmental effects of the disease or to the problems associated with family disruption, community rejection, and the resulting parental isolation, guilt, and alienation. In middle school, there may be additional emotional problems associated with physical changes, such as weight loss, and declining cognitive function. The family should be given maximum support by school mental health personnel.

TERMINAL ILLNESS

As the disease takes a downward course, the child’s capacity to be educated diminishes. The school can continue to serve an important need by assisting the family with counseling and emotional support and instructing classmates about the appropriate response to children with chronic and terminal illness.

CONFIDENTIALITY

As long as the presence of AIDS or HIV infection stigmatizes the patient and his family, confidentiality will continue to be an important issue in which the need to safeguard the rights of the patient must be balanced by the school’s request for information. The primary responsibility of the pediatrician is to serve the patient and the family. Because of the possible occurrence of fear and hysteria in the school, it is particularly important that disclosure of the child’s HIV status to anyone in the school be done only with the informed consent of the parents and age-appropriate assent of the child. Some parents may be unwilling to agree to even limited disclosure. This should not prevent the child from attending school. School absenteeism and the child’s cognitive deficits that result in
learning disabilities may require the use of special services, but these usually can be obtained without revealing the diagnosis. School personnel should realize that there are children with HIV infection about whom no one will be aware because the child is asymptomatic or undiagnosed. A successful AIDS education program, however, will reassure teachers about the nature of the disease and create a more accepting environment so that the school staff can feel more comfortable with educating the HIV-infected child if the diagnosis should become known.

HIV-infected children may need medication administered during the school day. These medications should be given in the manner developed for all children who require medication while in school as described previously. Because the nature of the medication which may identify a child as previously HIV-infected, only those who are involved immediately with the medication decisions in school need to be informed. In most circumstances, only the school medical advisor and school nurse will need such information. The decision for this limited disclosure should be made by the child’s physician and the parents (AAP. AIDS and ethical issues. Manuscript in preparation).

The child with HIV infection also should be protected against other contagious diseases, such as measles and chicken pox. Vigorous enforcement of immunization requirements in all school settings will reduce but not eliminate the risk of such exposures. Therefore, methods for protecting HIV-infected children from these exposures should be developed which fit local circumstance and family wishes for confidentiality.

CONCLUSION

As the incidence of HIV infection in children increases, so will the school population of children with this disease. With the advent of new drug therapy, it is likely that these children will have a longer survival resulting in an increasing number of HIV-infected children entering school. An understanding of the effect of chronic illness and the recognition of neurodevelopmental problems in these children is essential to provide appropriate educational programs. The Academy recommends that:

1. All children with HIV infection should receive an appropriate education that is adapted to their evolving special needs. The spectrum of needs differs with the stage of the disease.

2. HIV infection should be treated like other chronic illnesses that require special education and other related services.

3. Continuity of education must be assured whether at school or at home.

4. Because of the stigmatization that still exists with this disease, it is essential that confidentiality be maintained by limiting disclosures and disclosing information only with the informed consent of the parents or legal guardians and age-appropriate assent of the student.

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