AMERICAN ACADEMY OF PEDIATRICS

Committee on Pediatric AIDS

Disclosure of Illness Status to Children and Adolescents With HIV Infection

ABSTRACT. Many children with human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome are surviving to middle childhood and adolescence. Studies suggest that children who know their HIV status have higher self-esteem than children who are unaware of their status. Parents who have disclosed the status to their children experience less depression than those who do not. This statement addresses our current knowledge and recommendations for disclosure of HIV infection status to children and adolescents.

ABBREVIATIONS. HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency virus.

Disclosure of HIV infection status to children and adolescents should take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context.

Many children with perinatally acquired human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) are surviving to middle childhood and some to adolescence. By the end of 1997, there were over 8000 reported cases of AIDS in children younger than 13 years and over 3000 adolescents with AIDS.[1] The median survival for children with perinatal HIV infection has been reported to be between 8.6 to 13 years and between 36% to 61% of infants with perinatally acquired HIV are expected to survive to age 13 years[2]; the median survival of children after a diagnosis of AIDS is made is longer than 5 years.[3] Consequently, the disclosure of a diagnosis of HIV infection/AIDS to a child is becoming an increasingly common clinical issue. As some family members have been reluctant to discuss the nature of the illness with their infected child or adolescent, this statement gives recommendations for disclosure of illness to HIV-infected children and adolescents.

Considerable guidelines exist about the disclosure of a chronic illness to a child. In general, disclosure is geared to a child's level of cognitive development[4] and psychosocial maturity. For most illnesses, young children receive simple explanations about the nature of their illness and what their responsibilities are in caring for themselves. The exact diagnosis and prognosis of the disease are less important in early discussions with young children. As children mature, they should be fully informed of the nature and consequences of their illness and encouraged to actively participate in their own medical care. Children with a variety of chronic diseases, including those with cancer, have exhibited better coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness.[5,6]

Nevertheless, some parents and health care professionals are reluctant to inform children about their HIV infection status. Data from several centers indicate that between 25% and 90% of school-age children with HIV infection/AIDS have not been told they are infected.[7–9] Some of the reasons given by family members for not disclosing HIV infection/AIDS status are similar to reasons expressed by parents of children with other serious diseases, which include concerns about the impact that disclosure may have on a child's emotional health and fear by the parents that the knowledge will negatively affect a child's will to live. Additional reasons often given by parents of HIV-infected children include a sense of guilt about having transmitted infection to the child, anger from the child related to knowledge of perinatal transmission, and fear of inadvertent disclosure by the child. Disclosure of status by the child may lead to stigmatization, discrimination, or ostracism toward the child and other family members. Health care professionals and families are also concerned about the difficulty children have keeping a "secret" and limiting the disclosure to selected persons.

Parents may choose not to disclose the health status to their child because of difficulty in coping with their own illness. Denial is common, and parents may not be able to deal with their own infection with HIV or that of a family member. Accepting the full consequences of illness within a family and learning to cope can be a lengthy process for individuals with any chronic disease. Failure to cope with illness appropriately may signify psychosocial dysfunction that merits specific counseling and therapy for parents. Furthermore, while parents may be making requests for nondisclosure based on what they believe is best for their child, physicians also have a responsibility to make an independent assessment of a child's readiness for disclosure.

Families desiring to protect their children from certain problems by concealing information risk having encounters with other issues. Children may de-

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

velop inappropriate and hurtful fantasies about their illness. A conspiracy of silence surrounding children infected with HIV may isolate them from potential sources of support. In the unfortunate event of the death of a parent, the opportunity is lost for children to discuss their illness with that parent. Children also may inadvertently learn of the nature of their illness in a manner that is not supportive. If children find out their infection status from someone other than a parent, they may feel unable to confide in their parent or feel a need to conceal that they are aware of their diagnosis.

Studies on the impact of HIV infection/AIDS disclosure to children are limited.[7,8,10,11] Preliminary work suggests, however, that children who know their HIV status have higher self-esteem than infected children who are unaware of their status. Parents who have disclosed the status to their children experience less depression than those who do not.[7] Disclosure should not only take into consideration the child's age, maturity, and the complexity of family dynamics, but the clinical context as well.[8,10,11] In critically ill children, issues of dying rather than disclosure may be more appropriate to address.

Pediatricians may serve as advocates for children in their care to their parents. For adolescents, the American Academy of Pediatrics has established that health care professionals have an ethical obligation to provide counseling to respond to the needs of adolescent patients and to insure that adolescents have an opportunity for examinations and counseling apart from their parents.[12] Consequently, physicians should provide full disclosure of HIV status to their adolescent patients. Physicians are also obligated to encourage adolescents to involve their parents in their care. Adolescents need to be informed about their illness to assist in their own care and to reduce the risk of transmitting the infection to others through unprotected sex or behaviors associated with illicit drug use.[12,13]

Pediatricians should anticipate the need for eventual disclosure when caring for HIV-infected children. Although physicians can listen to and discuss with parents potential reluctance to disclose, pediatricians should not accept parental or guardian requests to withhold the diagnosis under all circumstances. Pediatricians need to inform parents that if older children question them about their HIV infection status they will answer direct questions truthfully. Although disclosure should occur in a supportive environment that optimally includes knowledgeable professionals and parents, some parents may decide to have professionals assume this responsibility. Ongoing counseling is required throughout the child's infection to obtain parental understanding of the importance of disclosure.[13]

The American Academy of Pediatrics recommends the following for disclosure of HIV infection/AIDS status to children and adolescents:

1. Parents and other guardians of an HIV-infected child should be counseled by a knowledgeable health care professional about disclosure to the child of their infection status. This counseling may need to be repeated throughout the course of the child's illness.
2. Disclosure of the diagnosis to an HIV-infected child should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances.
3. In general, younger children, if symptomatic with illness, are most interested in learning what will happen to them in the more immediate future. They do not need to be informed of their diagnosis, but the illness should be discussed with them. If children are informed of their diagnosis, considerable effort should be directed toward eliciting and addressing their fears and misperceptions.
4. The American Academy of Pediatrics strongly encourages disclosure of HIV infection status to school-age children. The process for disclosure should be discussed and planned with the parents and may require a number of visits to assess the child's knowledge and coping capacity. Older children have a better capacity to understand the nature and consequences of their illness. Considerable effort will need to be directed to facilitate coping with the illness. Symptomatic children, particularly those requiring hospitalization, should be informed of their HIV status. The likelihood of children inadvertently learning about their status in a hospital setting is high. Disclosure should optimally be conducted in a controlled situation with parent(s) and knowledgeable professionals.
5. Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behavior.
6. Adolescents also should be informed of their HIV status to make appropriate decisions about treatment and participation in clinical treatment trials. Physicians should also encourage adolescents to involve their parents in their care.

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Pediatrics 1999;103;164
DOI: 10.1542/peds.103.1.164

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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