School-related Issues Among HIV-Infected Children

Joyce Cohen, MPH*; Catherine Reddington, MPH*; Dawn Jacobs, RN‡; Regina Meade, ASS; Donna Picard, RNC¶; Kathy Singleton, RN¶; Dorothy Smith, RN‡; M. Blake Caldwell, MD**; Alfred DeMaria, MD*; Ho-Wen Hsu, MD*; the Massachusetts Working Group on Surveillance of HIV in Children, Massachusetts Department of Public Health; and the Centers for Disease Control and Prevention

ABSTRACT. Objective. Many children with human immunodeficiency virus (HIV) infection are surviving long enough to reach school age. This study describes issues related to school attendance and disclosure of HIV infection in a population of HIV-infected children.

Methods. A statewide pediatric HIV surveillance system was used to collect data on school-age (5 years old) HIV-infected children. In addition, HIV clinic nurses familiar with the child’s history participated in a cross-sectional survey that collected information on school-related issues during the 1993–1994 school year.

Results. Of the 92 school-age children, only 3 were too ill to attend school. Another 5 children were home-schooled. Of the 84 who attended school outside the home, 25% had severe symptoms of HIV infection (Centers for Disease Control and Prevention [CDC] clinical category C). Absence from school ranged from less than 2 weeks during the year for half of the children (51%) to more than 8 weeks for 9 children (12%). Twenty-nine percent of the children received medication in school, usually administered by the school nurse. Over two thirds of the 50 children ages 5 to 10 years had not been told that they had HIV infection. Only 1 of the 20 children more than 10 years of age was not aware of her HIV infection. For 53% of the children attending school, no school personnel had been informed of the child’s HIV infection. Administration of HIV medications at school, age of child, and treatment at one particular HIV clinic were associated with the parents’ decision to inform school personnel. In the 47% of cases where the school had been informed, school nurses were most frequently notified, followed by principals and teachers.

Conclusion. Only 3% of school-age children were too ill to attend school, and almost all were enrolled in public schools. The number of HIV-infected children reaching school age will continue to grow, and public schools will bear the responsibility for educating these children. Health care providers will increasingly be called upon to guide both educators and families to assure that HIV-infected children receive the best education possible. Pediatrics 1997;100(1). URL: http://www.pediatrics.org/cgi/content/full/100/1/e8; HIV, AIDS, school issues, confidentiality.

ABBREVIATIONS. HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency virus; CDC, Centers for Disease Control and Prevention; AAP, American Academy of Pediatrics; PSD, Pediatric Spectrum of Disease (study).

Children with human immunodeficiency virus (HIV) infection have been attending our nation’s schools in increasing numbers for over a decade. The estimated number of HIV-infected children living in the United States in early 1994 was 12 240, and 39% (4820) of those children were age 5 or older.1 An estimated 1630 HIV-infected children were born in 1993 alone and these children have a median life expectancy of 9.4 years;2 thus, many more HIV-infected children can be expected to enter and remain in school in years to come. As more children with HIV infection survive long enough to enter school, families and schools are faced with a number of complex medical and social issues.3–6 These issues include the impact of illness on school attendance, disclosure of HIV infection status, confidentiality surrounding disclosure, and medication use during school hours.

In the early years of the acquired immunodeficiency syndrome (AIDS) epidemic in this country, children identified with HIV infection were sometimes forced to leave their schools.7 In August 1985, the Centers for Disease Control and Prevention (CDC) first released guidelines regarding school placement of HIV-infected children.8 In March 1986, the American Academy of Pediatrics (AAP) issued similar guidelines,9 encouraging school attendance for most children with HIV infection. In some areas of the country, school system policies require that schools be informed about the attendance of an HIV-infected child.10 The Massachusetts policy, in keeping with state law regarding the confidentiality of medical information, leaves the decision to inform school personnel of a child’s HIV infection to the parents or guardians of each child.11

Although increasing numbers of school-age children with HIV infection are attending school, little has been written about their experiences. Previous studies of school-related issues among HIV-infected children have addressed placement in public
sions of HIV-infected children with hemophilia; 13,14 prenatal drug exposure; 5 and special service needs. 6 We undertook this survey to describe the experi-
ences of children of children with HIV infection in schools across Massachusetts. We examined whether the children had been told about their HIV infection status and whether schools knew of their infection. We also describe school absences due to HIV-related illnesses.

METHODS

The Pediatric Spectrum of Disease (PSD) study is a multicenter active surveillance study of pediatric HIV infection coordinated by the CDC. In Massachusetts, the PSD study is based at the State Public Health Department. Data collection began in 1989 and all children born after January 1, 1977 who were known to be HIV-infected or were born to HIV-infected mothers were eligible for inclusion.

Children were identified through HIV clinics at each hospital site. Study nurses at each site abstracted all available medical records at initial enrollment and provided updates at 6-month intervals. The information collected on each child included demographic and social characteristics, mode of HIV exposure, clinical symptoms, HIV-related treatment, and laboratory data. Patient confidentiality was protected by identifying children only through an alphanumeric code. Data forms containing only the patient codes were sent to the PSD study for data entry. Data were collected at seven medical centers that included all pediatric HIV clinics in the state. Yearly surveys of all pediatric care providers in the state were performed to validate that virtually all known HIV-infected children were seen at these medical centers.

The study population consisted of HIV-infected children enrolled in the PSD study who were born before 1989 and were still alive and being monitored in 1993. In addition to demographic and clinical information routinely collected by the PSD study, specific information about the 1993–1994 school year—including each child’s type of school and grade, absences, medications, and whether the child and school were told about the child’s HIV infection—was collected on standard forms after the end of the school year. This information was obtained by PSD study nurses who also provided HIV care to the children and were informed about school issues because they either received home-based schooling (n = 5) or were considered by their parents to be too ill to attend school (n = 3).

Clinical Status

Fig 1 shows the CDC clinical stage of illness15 for children attending school during the 1993–1994 school year. Twenty-five percent had severe symptoms of HIV infection (category C), 55% had moderate symptoms (category B), and only 20% had mild or no symptoms (category N or A). Twenty-nine percent of the children had CD4 T-lymphocyte counts of 200 or less, 34% between 201 and 500, and 38% over 500. Thirty-three (33%) of the children had been diagnosed with at least one AIDS-defining condition. Four children attending school had gastrostomy tubes for nutritional supplementation. Three (4%) of the children attending school died during the school year.

RESULTS

Patient Population

Of the 100 eligible children, 97 had surveys completed by nurses at the five clinics where these children receive medical care. Of these, 5 children born in 1988 had not yet started kindergarten in 1993 and were excluded from the analysis. (One clinic caring for only 2 school-aged children was grouped with another nearby clinic.) Demographic characteristics for the 92 school-age children are shown in Table 1. The overall mean age of the children was 8.5 years (median 8, range 5 to 17). The mean age of the 77 children with perinatally acquired infection was 7.5 years (median 7, range 5 to 15), compared with a mean age of 13 years (median 13, range 10 to 17) for the 15 children with hemophilia-related or transfusion-acquired infection. Thirty-nine percent of the children were black, 33% were white, and 28% were Hispanic; 54% were male and 46% were female. More than half of the children (58%) lived with a biological parent, and most (83%) attended public school. Eight children were excluded from analysis of school-related issues because they either received home-based schooling (n = 5) or were considered by their parents to be too ill to attend school (n = 3).

School-related Issues

Table 2 shows school-related information for the 84 children who attended school outside the home. Most of the children were in elementary school (grades kindergarten through 5). Six percent of the children received some tutoring during the school year. Ninety-seven percent of the children were taking antiretroviral medication; however, only 29% of the children received medications while in school (Table 2). Of these, 74% had their medication administered by the school nurse. All children who self-administered their medication were in grade 8 or above.

Forty-nine percent of children missed 2 or more weeks of school, and 12% missed more than 8 weeks. Five children had absences related to nonmedical issues as well as HIV: 3 missed school because of their mother’s illness, and 2 because of social issues not related to HIV. Of the children with mild symptoms, 75% were absent for less than 2 weeks, compared with 51% of children with moderate symptoms and 27% of children with severe symptoms ($P < .01$). Twenty-three children (27%) were hospitalized a total of 44 times during the school year (September through June) with a range of 1 to 5 hospitalizations per child. The mean number of hospital days per child was 5.5. Seventy-four percent of the hospitalizations were for stays of 1 week or less.

Disclosure of HIV Infection to the Child and School

Thirty-seven children (42%) had been told that they had HIV infection. The average age at disclosure was 8 years. Fig 2 shows the proportions who had been told of their HIV infection by age. Over two-thirds of children ages 5 through 10 years had not been told that they had HIV infection, whereas only 1 of the 20 children over age 10 years did not know, a 14-year-old girl who was described as being cognitively limited. Clinical severity of the child’s symptoms was not associated with whether or not the child was told of his/her disease status. Forty-eight percent of children with severe symptoms had been told compared with 39% of children with mild to moderate symptoms. There was also no difference between children living with biological parents (39% informed) and children living with other primary caregivers (45% informed). Among the children who had been told, initial disclosure was most often done by family members alone (59%), by a family caregiver (45% informed) and children living with other primary caregivers (45% informed). Among the children who had been told, initial disclosure was most often done by family members alone (59%), by a family member together with medical staff (24%), or by medical staff alone (16%) at the request of the family.

Forty-seven percent of the families had informed someone in the school of their child’s HIV infection. In 26% of cases where the school was informed, medical and/or social service staff from the HIV clinic had assisted the family in informing and educating school personnel. Although more than one school official was frequently informed, the decision regarding who to inform was made by the family. School nurses, principals, and classroom teachers, in that order, were the most likely to be informed by families (88%, 62%, and 47%, respectively).

We next examined whether any demographic or clinical factors were associated with families choosing to inform the school about their child’s HIV infection. Schools were more likely to be informed about children who were ≥9 years old, took medication at school, and were cared for at clinic C (Table 3). In a multiple logistic regression model, only medication taken during school and treatment at HIV clinical care center A remained independently associated with informing school personnel. Ninety-one percent of the children at clinic C had informed someone in their school, compared with 15% to 51% at the other clinic sites. In addition, 64% of children seen at clinic C

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of hospitalizations</td>
<td>0</td>
<td>61 (73%)</td>
</tr>
<tr>
<td></td>
<td>1–2</td>
<td>17 (20%)</td>
</tr>
<tr>
<td></td>
<td>3+</td>
<td>6 (7%)</td>
</tr>
<tr>
<td>Total school missed</td>
<td>&lt;2 wk</td>
<td>37 (51%)</td>
</tr>
<tr>
<td></td>
<td>2–4 wk</td>
<td>19 (26%)</td>
</tr>
<tr>
<td></td>
<td>4–8 wk</td>
<td>8 (11%)</td>
</tr>
<tr>
<td></td>
<td>&gt;8 wk</td>
<td>9 (12%)</td>
</tr>
<tr>
<td>Repeated at least one grade</td>
<td>10 (14%)</td>
<td></td>
</tr>
<tr>
<td>HIV-related medications administered at school</td>
<td>23 (29%)</td>
<td></td>
</tr>
<tr>
<td>Administered by:</td>
<td>School nurse</td>
<td>17 (74%)</td>
</tr>
<tr>
<td>[n = 25]</td>
<td>Child</td>
<td>6 (26%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child</td>
<td>≥8 years</td>
<td>14/41 (34%)</td>
</tr>
<tr>
<td></td>
<td>≥9 years</td>
<td>20/32 (62%)</td>
</tr>
<tr>
<td>Mode of transmission</td>
<td>Perinatal</td>
<td>25/60 (42%)</td>
</tr>
<tr>
<td></td>
<td>Hemophilia/ transfusion</td>
<td>9/13 (69%)</td>
</tr>
<tr>
<td>Clinical severity</td>
<td>Mild</td>
<td>7/16 (44%)</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>14/36 (39%)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>13/21 (62%)</td>
</tr>
<tr>
<td>HIV clinical care center</td>
<td>A</td>
<td>3/12 (25%)</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>19/37 (51%)</td>
</tr>
<tr>
<td></td>
<td>C</td>
<td>10/11 (91%)</td>
</tr>
<tr>
<td></td>
<td>D</td>
<td>2/13 (15%)</td>
</tr>
<tr>
<td>HIV-related medication taken at school</td>
<td>Yes</td>
<td>21/23 (91%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>13/50 (26%)</td>
</tr>
</tbody>
</table>

Fig 2. Proportion of school-age children who had been told of their HIV infection, Massachusetts, 1993–1994.
knew their HIV status, compared with 20% to 40% of children at other sites.

For some of the children in our study, only the school or the child (but not both) knew of the child’s HIV infection. Thirteen children (18%) had not been told that they were infected, but school personnel had been informed. Conversely, 10 children (14%) knew they were infected, but their families had not informed the school.

**DISCUSSION**

This study of a population-based sample of school-age children focuses on disclosure of the child’s HIV status to the child and to school personnel. One of the most difficult issues for parents is deciding when and how to tell HIV-infected children about their diagnosis. We found that by age 10, over half of our children had been informed, similar to the findings of Grubman et al16 in their cohort of older children. Our study also included younger school-age children, most of whom had not been told that they were HIV-infected. Although young children with cancer are now commonly told their diagnosis when treatment for their disease is begun, the social issues surrounding a diagnosis of HIV infection make disclosure a much more complex issue.17

Disclosure may often be contemplated by parents or guardians, but many feel unprepared to face the sensitive questions that may arise following disclosure. Many children already know or suspect their diagnosis even if no one has actually discussed it with them.18 Parents often turn to medical personnel for guidance and support on this issue. In over one third of our families whose children had been told that they had HIV infection, a member of the health care team had been present when the child was first informed. Although the questions of when and how best to inform a child remain unanswered, there is general agreement that children of normal cognitive development can benefit from the opportunity to openly discuss their illness with adults whom they trust.19

The decision to inform school personnel of a child’s HIV infection is associated with tremendous anxiety for the family, who needs to weigh the potential benefits of disclosure with the fear of discrimination or loss of privacy. Several families were influenced by published reports of how their school system or community had responded to previous disclosures about HIV-infected students. Because medical management of this disease plays such a large part in an HIV-infected child’s life, confidentiality becomes increasingly difficult to maintain as the disease progresses. The administration of medications in school was a strong predictor of whether the school was informed of the diagnosis. Families who choose not to inform the school may have to arrange complex medication schedules to avoid administration during school hours. One older child in our study took his medication in the school bathroom to avoid having to inform the school nurse.

The other key predictor of whether families chose to inform the school was treatment at a particular HIV clinic, possibly indicating the influence of medical personnel on the family’s decision. Wiener and Septimus20 have outlined the many ways in which the health care team can be helpful to families in their interactions with the school system. The staff at HIV clinic C actively encourages families to inform the school, often accompanying the parents to meetings with school personnel. Support from health care providers may increase the family’s ability to talk openly about their child’s illness. Close communication between the health care team and school personnel can also help to address concerns the school may have about the care of these children. All of our HIV clinics reported that the continued contact they had with the schools revolved around medical issues, including immunizations, medications, absences, illnesses, and participation in school activities.

The difficulty of maintaining confidentiality when the family had not disclosed the child’s HIV status to the school was a recurrent theme reported by many of the HIV clinic nurses. Children may be faced with questions from school personnel and classmates because of repeated absences and hospitalization. School personnel may suspect or assume the diagnoses even if they have not been officially informed. When a child whose HIV infection was not known to the school had medical problems that necessitated communication between the school and the clinic, medical personnel were required to avoid specific mention of HIV. A child’s schooling can also be disrupted when a family does not feel comfortable about informing the school of the child’s infection. One family removed their child from a school because the teacher questioned the child about his illness. Neither the child nor the school knew of the HIV diagnosis at that time.

A major limitation of our study was that we received information from HIV clinic nurses instead of from direct interviews of the parents, children, or school officials. We also were unable to compare children’s school absences and grade performance with those of uninfected children living in similar environments. Further research is needed to study the complex social support needs of the HIV-infected child as well as the support that school personnel may need when a student is identified as HIV-infected. A better understanding of the impact of the illness and death of HIV-infected children on their classmates is also of interest.

The findings that only 3% of school-age HIV-infected children were too ill to attend school and that most were enrolled in public schools indicates that public school systems are bearing the major responsibility for educating HIV-infected children. A recent survey of the largest school districts in the country shows that school systems have in fact begun to formulate policies that respect the privacy of the family while not compromising the child’s education.21,22

Although the decision to inform the school about a child’s HIV infection rests with the family in most cases, the health care team can be instrumental in assisting the family in making their decision and serving as an advocate for the child in the educa-
tional system. Health care providers should offer guidance to school personnel regarding the medical issues that may arise for the HIV-infected child while under their supervision. Communication between health care providers and school personnel is essential for meeting both the medical and educational needs of the HIV-infected child.

ACKNOWLEDGMENTS

This research was supported by contract U64/CCU101187 from the Division of HIV/AIDS at the US Centers for Disease Control and Prevention.

We thank Jeanne Bertolli for her support and helpful discussion.

Members of the Massachusetts Working Group on Surveillance of HIV in Children: Baystate Medical Center, Barbara Stechenberg, MD; Boston Children’s Hospital, Kenneth McIntosh, MD; Boston City Hospital, Stephen Pelton, MD; Massachusetts Department of Social Services, Suzanne Tobin, RN; Massachusetts General Hospital, Mark Pasternack, MD; New England Medical Center, Cody Meissner, MD; and University of Massachusetts Medical Center, John Sullivan, MD.

REFERENCES

15. Centers for Disease Control and Prevention. 1994 Revised classification system for human immunodeficiency virus infection in children less than 13 years of age. MMWR. 1994;43:1–10
School-related Issues Among HIV-Infected Children
Joyce Cohen, Catherine Reddington, Dawn Jacobs, Regina Meade, Donna Picard, Kathy Singleton, Dorothy Smith, M. Blake Caldwell, Alfred DeMaria, Ho-Wen Hsu, the Massachusetts Working Group on Surveillance of HIV in Children, Massachusetts Department of Public Health and the Centers for Disease Control and Prevention

*Pediatrics* 1997;100;e8
DOI: 10.1542/peds.100.1.e8
School-related Issues Among HIV-Infected Children
Joyce Cohen, Catherine Reddington, Dawn Jacobs, Regina Meade, Donna Picard, Kathy Singleton, Dorothy Smith, M. Blake Caldwell, Alfred DeMaria, Ho-Wen Hsu, the Massachusetts Working Group on Surveillance of HIV in Children, Massachusetts Department of Public Health and the Centers for Disease Control and Prevention

Pediatrics 1997;100;e8
DOI: 10.1542/peds.100.1.e8

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/100/1/e8