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Ellen R. Cooper
Boston University

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AIDS in Children: An Overview of the Medical, Epidemiological, and Public Health Problems

Ellen R. Cooper, M.D.

Cases of AIDS in children under thirteen years of age have been described since 1982. Diagnosis is more difficult in children than in adults, owing to the more varied clinical presentation and the difficulty in interpretation of laboratory tests. Current diagnostic criteria of HIV infection are reviewed, as well as symptomatology, natural history, and controversies surrounding management and therapy. Without a full appreciation of the transmissibility of HIV, issues including school and day-care attendance and foster family placement remain emotionally charged. Conflicting public policies contribute to fears on the part of the general public. Because of the unique implications for the entire family when a child is found to have HIV infection, the health care profession has been obliged to confront complex psychosocial issues unparalleled in modern medicine. The medical community may provide one safe environment for the family, and so the burden of providing support falls to a profession only variably trained and equipped for this task. In the absence of a vaccine or a cure, public education directed at primary prevention and reduction of stigmatization are the keys to true control of the epidemic.

The acquired immunodeficiency syndrome (AIDS) was first described in homosexual males and intravenous drug users. It was recognized subsequently in recipients of infected blood products and in heterosexual partners of infected individuals. More recently, AIDS has been described in the population of infants born to infected mothers. In 1982, the first descriptions of this illness in children were reported. Retrospectively, however, cases can be diagnosed since 1979 in this young population. The total number of pediatric cases of AIDS reported to the Centers for Disease Control (CDC) was 820 as of February 8, 1988, but by 1991 this number is expected to reach over 3,000.¹

The CDC has established strict criteria for the case definition of AIDS. Although these criteria continue to be revised, it must be underscored that many cases of symptomatic HIV infection may be excluded from the CDC count. Current studies of seroprevalence in newborns indicate that in the inner city of Boston, 1 in 55 babies may be HIV-positive at birth.² This approaches the highest rate of seroprevalence among newborns in New York City.³ Many, but not all, of these children will go on to develop symptomatology. The true

¹ Dr. Ellen R. Cooper is assistant professor of pediatrics in the Division of Infectious Diseases at the Boston University School of Medicine, and is director of the Pediatric AIDS Program at Boston City Hospital.
impact of this statistic with respect to pediatric AIDS will be addressed later in this article.

Widespread recognition of pediatric AIDS as a specific disease entity was delayed for several reasons. It was difficult to differentiate AIDS from other, already described causes of congenital immunodeficiency syndromes. This differentiation required an elaborate combination of epidemiological observations, pathological studies, and specific laboratory testing.

The clinical picture of AIDS in children remains quite distinct from that in adults. In general, there is a greater heterogeneity in the clinical presentation of pediatric AIDS. Although the well-known opportunistic infections seen in adult AIDS are also seen in some pediatric cases, other infectious agents are common. In contrast to adult cases, the types of pediatric infections first noted were bacterial, usually presenting as sepsis or meningitis. Primary viral infections with herpes virus or cytomegalovirus were also documented, but it remained difficult to prove the causal association with the now well-known retrovirus without more specific testing. Because of this and the relatively small number of cases, it was difficult to establish epidemiological associations early in the epidemic. There is also a greater severity of clinical disease in infants with AIDS, especially when those without opportunistic infections are compared to adults. Death often occurs early, sometimes before criteria are met to definitively establish the diagnosis of AIDS, thereby further complicating epidemiological surveys and investigations. These factors undoubtedly contributed to difficulties in accepting early reports of AIDS in infants, and continue to cloud efforts to define AIDS in pediatric patients.

In order to help with the appropriate diagnosis of what was a newly described disease, the Centers for Disease Control established specific case definition criteria for pediatric AIDS in 1984. These criteria required modification a year later, as it became more and more clear that the disease differed from AIDS in adults. In 1987, the CDC again revised its definition. It developed a definition of AIDS in children under thirteen years of age, as well as a classification schema for other forms of HIV infection in these children. The system was designed to aid epidemiological studies, disease surveillance, prevention programs, and health care planning and policy. So established, it is useful primarily in the establishment of public health guidelines. It is less useful clinically, and individual patients must be considered separately with regard to management and prognosis.

Current Diagnosis

Ideally, HIV infection in children is identified by the actual presence of the virus in blood or tissues. This may be confirmed by culture or antigen detection methods. Since these techniques are not standardized tests as of yet, they are not readily available in most centers. In most areas, physicians must rely on the presence of antibody in the serum as evidence of HIV exposure. This creates a particularly confusing situation when the infant is born to an infected mother. It is currently believed that the maternal antibody passively acquired by the infant from the mother while the infant is in utero may persist for up to fifteen months. If the child demonstrates persistence of HIV antibody for longer than fifteen months, he or she is considered to be truly infected, regardless of whether symptoms are present at that time. The problem arises in the child under fifteen months of age who is seropositive. Seropositivity in the asymptomatic infant cannot be used to definitively establish HIV infection. It is, however, an important marker, since it can certainly identify the infant at highest risk. If actual virus cannot be demonstrated in the blood or tissue by antigen or culture techniques, the child may be considered infected only if there
is evidence of cellular and humoral immune deficiency as well as clinical symptomatology. These symptoms may include progressive neurological disease, specified secondary infectious diseases, secondary malignancies, or lymphoid interstitial pneumonitis. This last entity is a histologically unique condition that causes a chronic and debilitating lung disease in many children. As noted earlier, the definition of childhood AIDS remains extremely restrictive as to the type and severity of symptoms; thus, there is an underreporting of this disease in the United States. The new classification schema, it is hoped, will permit the identification of all children with AIDS as well as other forms of severe HIV infection. It is also hoped that the new schema will ensure that all children with HIV infection will be eligible for needed services and that these services will not be limited by statutory or regulatory definitions of AIDS.

Natural History of Disease

The natural history of disease after HIV seroconversion in the pediatric age group is not completely clear at this time.

The incubation period in the congenitally infected infant seems to be four to six months, but it can be longer than five years in the transfusion-infected child. Most cases of pediatric AIDS occur in very young children, with 50 percent of pediatric AIDS diagnosed during the first year of life and 82 percent by the age of three years.\(^4\)

Although the clinical picture of congenital infection can and does vary significantly, a profile has been suggested. Common features include failure to thrive, lymphadenopathy, hepatospleno megaly, chronic diarrhea, mucocutaneous candidiasis, and parotitis. Other hallmarks are recurrent fevers and bacterial and viral infections as well as interstitial pneumonitis. Children with lymphoid interstitial pneumonitis tend to become symptomatic later and have a better prognosis. Follow-up has not been extensive enough to provide true estimates of mortality, but CDC figures show that over 61 percent of children reported with AIDS are known to have died.\(^5\)

Transmission

Since HIV infection in infants and children in this country is a relatively recent occurrence, a clear understanding of the modes of transmission is still evolving. It is well known that in adults the major routes for HIV infection are close sexual contact, particularly male homosexual contact; the sharing of needles and syringes in intravenous drug users; and the receipt of blood or blood products.

In the older child, HIV can be associated with these same established routes of infection. The number of AIDS patients identified during adolescence remains very low; this may be explained by the long latency period of the virus. Behaviors commonly accepted as high-risk may be initiated during these years, but symptoms of the disease may not become evident until young adulthood. Adolescents should therefore be considered a target population for education, counseling, and testing. Like adults, children have been exposed to HIV during blood transfusions; these cases currently represent 13 percent of all cases of AIDS in childhood. Another 5 percent of childhood AIDS cases can be attributed to blood products received as treatment for coagulation disorders.\(^6\) There have also been a few reports of HIV transmission to children occurring as the result of sexual abuse.

Most children with AIDS, however, are born to mothers who themselves carry the virus. This perinatal exposure accounts for 80 percent of the children with AIDS.\(^7\) Such
mothers may have a history of intravenous drug use, prostitution, or multiple sexual partners. They may practice no high-risk behaviors but simply originate from particular geographic regions where heterosexual transmission is thought to play a major role. Here in New England we see a great number of patients from Haiti and central Africa, both of which are considered endemic areas at this time. At the time of their pregnancy, these mothers may be symptomatic, have AIDS or ARC, or be totally asymptomatic. Many are unaware of their HIV antibody status, thus increasing the difficulty in recognition of children at risk for congenitally acquired HIV infection.

The proof of transplacental transmission of HIV includes the suggestion by some investigators that HIV-infected infants have characteristic at birth. This would imply an embryopathy secondary to fetal infection. This suggestion remains controversial, and more children will be evaluated before it can be substantiated. The virus has been isolated from the tissues of fetuses as well as from umbilical cord blood, and this stands to indicate the presence of viral transmission from mother to infant. Transmission has been documented in infants who have been born by Caesarean section and so have had no exposure to vaginal secretions during the birthing process. In addition, infants have been found to be seropositive, and later symptomatic, even in instances when there has been no postnatal contact with the biological mother.

The incidence and the efficiency of HIV transmission in utero have not yet been well defined. It does seem clear at this point, however, that transmission of the virus to the fetus, while common, is not inevitable. With regard to twins, cases have been reported in which only one infant was infected. By most conservative estimates, however, approximately 60 percent of infants born to mothers who are themselves seropositive are infected with HIV. There are no data to suggest that Caesarean section would lower the incidence of HIV transmission from mothers to infants, but this is certainly a question that has been raised in the medical community. Many studies are being conducted around the world in order to obtain better answers to this very important question. In Boston alone, several studies are trying to investigate the efficiency of transmission, the presence or possible importance of other cofactors that may impact on that transmission, and the effect that pregnancy itself may have on the progression of the disease in a seropositive woman.

Other types of perinatal transmission of HIV must be considered, although they probably do not play as major a role as transplacental passage of virus. These include passage of the virus via infected breast milk. In support of this as a potential risk, there has been a report of a child born by Caesarean section to a mother who received blood contaminated with HIV after the delivery of the infant. This child seroconverted, with the only identifiable exposure being breast milk.

Although actual infective virus seems to be transmitted in approximately 60 percent of cases, there is a passive transfer of maternal antibody in virtually 100 percent of infants born to mothers who are themselves seropositive. This raises all sorts of social, political, and medical dilemmas, since currently we are unable to identify those infants who are most likely to become symptomatic. In those infants who are not truly infected, maternal antibody seems to decrease over months, until finally the babies become seronegative. Because this may take up to fifteen months, decisions regarding day care, immunizations, and treatment modalities often become an issue before the question of true infectivity can be resolved satisfactorily.

The actual incidence of HIV infection in infants will depend on several factors. These include the number of children born to HIV-infected women as well as the prevalence of seropositivity in the population of women who are of childbearing age. The prevalence of
HIV has been clearly shown to be dependent on the subpopulation group and the geographic area studied. For example, 59 percent of intravenous drug users in New York City are seropositive, while only 20 to 25 percent of intravenous drug users in Boston seem to be seropositive. In Worcester, this percentage was even lower but has recently been found to be increasing rapidly. As the number of infected women continues to rise, we can expect the incidence of HIV-infected infants to increase enormously.

The possibility of transmission of virus to family members and household contacts has been a particularly sensitive issue. To date, in spite of exhaustive studies, there has been no evidence to support the horizontal transmission of HIV with casual or usual household contact. In one family study, a mother who cared for her transfusion-infected child did seroconvert, but this was after very heavy and unusual exposure to blood, secretions, and excreta without proper hand washing or the use of gloves. In another study, a brother of an HIV-infected child did become seropositive. The only unusual exposure that was documented was a bite from the infected child. The causal relationship has not been positively determined in this case. Although HIV has been cultured from both tears and saliva, these are considered to be fluids with a very low titer of virus, and to date there have been no reports of transmission via exposure to these secretions.

A question has been raised as to the susceptibility of the infant and the young child to HIV. Although more investigation is needed before a clear understanding can be acquired, it seems that increased susceptibility may indeed be a factor, as evidenced by several epidemiological studies. In a study of transfusion-related AIDS, infants accounted for 10 percent of cases even though they had received only 2 percent of the total number of blood transfusions. There also seemed to be a shorter latency period between exposure to virus and onset of symptoms. This may be attributed to the relative size of transfusion, and therefore the load of virus.

Controversial Management Modalities

The mainstay of the management of the child with HIV infection has been largely a supportive one. Prompt recognition and treatment of all infections are of the utmost importance, as is the maintenance of good nutritional status. However, a few issues have prompted debate among the health care professionals who are caring for these children.

The utilization of immunizations has been controversial in the population of children infected with HIV. The potential hazards of the vaccines themselves must be weighed against the risk from the diseases they are designed to prevent. It has been suggested that the stimulation from the vaccine itself may cause a deterioration in the clinical status of an infected child.

The risk of live virus vaccines such as MMR (measles/mumps/rubella) and oral polio vaccine has been specifically debated. In general, children who are immunocompromised by other deficiencies or by chemotherapeutic ablation are at risk for acquiring the disease from a vaccine of this type. These vaccines are therefore not recommended for this population. With regard to HIV-infected children specifically, several retrospective studies have investigated the outcome when seropositive children were inadvertently given oral polio vaccine. Because no ill effects have been reported, and because not all seropositive infants are truly HIV-infected, current recommendations from the CDC suggest that if the child is asymptomatic it may be safe to administer routine immunization. Specific recommendations of the national Immunization Practices Advisory Committee in regard to the immunization of HIV-seropositive children have been published, but differences of opin-
ion still exist.\textsuperscript{14} Some feel that the theoretical risk is quite substantial and that until a large number of children have been studied, it may be wise to be conservative. At Boston City Hospital, we recommend the use of inactivated polio vaccine in all seropositive children, whether symptomatic or not. We feel more comfortable with this practice not only with respect to the infant’s safety, but also because these children often have infected caretakers. Polio virus is shed in the stool for weeks to months after oral vaccine is given, and this would put infected guardians at some risk as well. We remain consistent in our view of the risk associated with live virus vaccine and thus withhold measles/mumps/rubella immunizations from seropositive children as well, although this represents no risk to other family contacts.

Inactivated polio vaccine is often difficult to obtain; when it is available, it is more costly than oral, live vaccine. In areas where immunization practices are being debated, the theoretical risk of the oral vaccine must be weighed against the relative accessibility of the inactivated form. Other routine vaccinations of childhood should be given, although some data suggest that the vaccine may not result in the production of functional antibody. When exposure to chicken pox occurs, these children should also be given passive immunization, although efficacy has not yet been determined.

The biggest problem in the management of the child with HIV infection is control of the recurrent infections that may progress to sepsis, pneumonia, and meningitis. Optimal strategies to prevent this have not yet been established. Many centers have recommended the use of prophylactic antibiotics, but these carry with them the risk of side effects, poor compliance, and the emergence of resistant bacterial strains.

Given the predisposition of children with HIV infection to develop recurrent bacterial infections, the use of prophylactic intravenous immunoglobulin (IVIG) has been suggested. A few studies have been reported, but no firm data that are based on controlled clinical trials are available. Because of a lack of other effective therapies, these early, subjective reports resulted in fairly widespread use of this preparation. Now, with the number of HIV-infected children climbing rapidly and the average cost per child of monthly IVIG totaling approximately $30,000 per year, there is pressure to demonstrate efficacy. In addition, some feel that monthly visits to the hospital for intravenous therapy may represent undue exposure to other infectious agents. Currently, a multicenter study funded by the National Institutes of Health is executing a double-blind placebo-controlled trial to address this issue rapidly and accurately. The Boston University School of Medicine is actively participating in this trial.

\textbf{Special Antiviral Therapies: Choices and Dilemmas}

The devastating and frequently occurring central nervous system disease in children with HIV infection has to be taken into consideration when a specific antiviral agent is chosen for study. Any antiviral drug that does not penetrate the blood brain barrier may be of little benefit in the pediatric age group.

As new antiviral agents become available for study in children with HIV infection, it will be important to have modes of comparison already established. In this way, all children will be able to receive therapy already proven to have some efficacy, either in control of symptoms or in activity against the retrovirus. The ultimate goal of therapy for HIV infection would be to control or ablate the infection altogether, and also restore the individual’s ability to reconstitute normal immune function.
Although there are many potential targets for antiviral drugs, most recent efforts have been aimed at inhibiting the DNA polymerase that is unique to the retrovirus. Of the candidate antiviral agents for testing in children, the most publicized has been Azidothymidine (AZT). Preliminary trials have already begun in several centers so that optimal dosage regimens can be established. Although AZT has been shown to be efficacious in adults with AIDS and has been licensed for clinical use, it is not without problems. It is quite toxic, and most patients taking it have developed anemia severe enough to necessitate blood transfusion. Other cell lines of the bone marrow may also be affected. In addition, there may be other side effects, such as nausea, vomiting, and central nervous system disturbances. Although HIV antigen has been demonstrated to decrease during AZT therapy, it returns with cessation of treatment. AZT must therefore be considered lifelong therapy. It is not known how children will respond to this drug.

Severe opportunistic infections with viral, bacterial, and parasitic pathogens have spawned active research in the area of new therapies for these specific pathogens as well. New drugs have been developed and tested for cytomegalovirus, herpes, and Pneumocystis carinii infections. While these therapies may have no effect on HIV per se, they have had a great impact on the care of the infected patient.

Many AIDS patients, both adult and children, have received new therapies of one sort or another on experimental protocols after informed consent has been obtained. This has created a legal dilemma, especially in regard to the pediatric patient. Many of these children are in foster care families, with legal custody being in the hands of the state social services department. This brings up many legal questions of risk and liability on the part of the governmental agency that grants permission for participation in experimental protocols.

Of course, this problem is unique to pediatrics, since the patient is a minor and is therefore unable to give informed consent on his or her own behalf. Traditionally, it has been difficult to obtain permission in circumstances such as these. However, as more and more protocols become available, and as the number of children with devastating disease increases, these “experimental” therapies will become standard of care. The legal questions regarding liability will need to be weighed against the ethical issue of withholding possible effective therapy from children with otherwise fatal disease.

Public Health and Policy Issues

Education and day care of children with HIV infection is an emotionally charged topic, because of the severity of disease and the fear on the part of the general public. Pressure on those who make public policy has prompted hasty and sometimes overly conservative decisions. It is important to underscore again that there has been no documentation of HIV transmission in the school, at day care, or in any other casual setting.

Current guidelines from the Centers for Disease Control confirm that school-age children who have evidence of HIV infection can be comfortably included in the classroom setting. Certain unusual circumstances, however, do require special consideration in this regard. For example, children who have oozing lesions or recurrent bleeding or who lack control of their bodily secretions may pose a greater risk to their classmates. Moreover, children who may not be developmentally appropriate and who may therefore exhibit abnormal behavior, such as excessive biting, may need to be excluded from the general classroom. Although it is still unclear whether even these children truly represent a sig-
significant risk to their classmates, the Massachusetts Governor's Task Force on AIDS has upheld the CDC guidelines.

Currently, the true responsibility for creating guidelines to deal with this sensitive issue falls to local authorities. The guidelines are much more restrictive in some states than in others. Still other states have avoided the issue when possible. These discrepancies further fuel apprehensive parent and political groups, by underscoring the uncertainty on the part of policymakers as to the real danger that might exist. The Report of the Surgeon General's Workshop on Children with HIV Infection and Their Families, published in July 1987, suggests that the decision about whether to attend school is best left to the individual's physician.\textsuperscript{15} This decision should be based on the general health of the individual and on a judgment as to whether school attendance would indeed pose a risk to the patient by way of excessive exposure to infectious agents. The report states that under ideal circumstances, an individual at the school should be aware of the diagnosis; however, the need for confidentiality gives children the right to have the information withheld from the school. The report emphasizes that realistic guidelines based on best current knowledge should be considered by school boards, principals, and physicians. Resources should be developed for dissemination and implementation of new information as it becomes available. The report also deals with the issue of day care for the preschooler or the developmentally delayed older child. It suggests that these toddlers be allowed to attend day care unless scientific evidence suggests that exposure of this sort could place at risk the other, uninfected children. So far, investigators have been unable to collect this evidence, and for this reason these children should not be excluded from day care arrangements.

In Massachusetts, conservative guidelines exclude children under three years of age with evidence of HIV infection from attending a group day care setting. This raises issues of ethical, political, and economic importance. While health care workers try to encourage HIV testing in high-risk populations, the day care guideline represents yet another negative incentive to families. With no alternative to day care, one or both parents may be forced out of the workplace to stay at home with the child. Coupled with the fact that one adult may be symptomatic from HIV infection, this adds yet another burden to an already stressful situation. Because the guidelines pertain to those infants who merely have evidence of maternal antibody (since it may not be possible to distinguish these children from those with true infection), the problem is aggravated still further. Counselors and health care workers are often faced with a difficult dilemma. Reporting to day care organizers may represent a breach of confidentiality, and so infringements of state regulations may go uncorrected anyway. The question of legal obligation in these circumstances is a most difficult one, and ultimately may have to be resolved by the judicial system.

Another area where lack of federal guidelines has forced local authorities to make difficult decisions is foster care. Because legal custody is in the hands of a government agency when a child is placed in foster care, the question of informed consent for HIV testing is a sensitive one. Physicians can obtain approval for testing from most social service agencies, but confidentiality guidelines vary. In some cases, foster families are not informed of the test results. This raises obvious questions of liability, since precautions for family members and medical care for the child in question may not be adequately addressed.

**Psychosocial Issues and Counseling**

Aside from all of the new and unusual questions that have been raised with regard to HIV, the psychosocial issues have created new challenges to the health care system. The stigma-
tization of this disease has complicated the health and social care of the infected individuals. School-age children have become the focus of teachers', other pupils', and neighbors' fears. Ostracism and resultant low self-esteem have often been the outcome of this public frenzy and fear. Adolescents who have acquired this disease by engaging in "high-risk behaviors" must deal with admissions to the behaviors in addition to the disease itself. Well-publicized incidents of discrimination, accompanied at times by acts of violence, have created an environment in which the family with an infected individual has sometimes chosen to be totally anonymous rather than search for help. This reduces the possibility of psychiatric, social service, religious, or community support.

In addition, the misconceptions within different cultural, ethnic, and even community groups have further complicated the feeling of alienation on the part of the afflicted family. Some individuals have been forced out of housing, others turned away by their family or friends. In some cases, churches have been afraid to give comfort to these families, even refusing to house funeral or memorial services. In addition to the obvious psychosocial burden on the family, this places a great stress and responsibility on the medical community, since it is often only through this system that any support may be obtained. This is considered a "safer" environment in which to vent frustrations, anger, and sadness surrounding the diagnosis; but it means that the medical staff often accepts this burden alone.

Identification of a seropositive infant brings up other problems for the family. Many of these children are already the victims of drug-using families and low socioeconomic status. When a mother is told that her infant is seropositive, she must also be told of the likelihood that she herself is infected with HIV. This message must convey the serious and usually fatal nature of the illness in the infant; the likelihood of infection and potential for illness and death in the parents; the need for changes in sexual expression in order to prevent subsequent transmission; and the possibility of avoidance of future pregnancies. Fear, guilt, and sadness further complicate an already complicated scenario. An older, uninfected sibling must face the possibility of losing not only a sibling, but both parents as well. This type of "family disease" has not been described or paralleled in modern medicine.

Any discussion of the psychosocial issues regarding HIV infection must include the medical team and other support services through which care is provided for the child. Because of the problems just discussed, caring for these patients can be a draining experience for the pediatricians, who usually see patients improve under their care. Even for physicians and others who care for chronically and terminally ill children, the family nature of this disease can be overwhelming. The social problems are far-reaching, and the feeling of impotence on the part of the medical team can reach a point of desperation. A large number of people are needed to care for a particular child, owing to the multidisciplinary nature of the required services, and this can lead to miscommunications. We have found that regularly scheduled discussion and support groups are necessary for dealing with this situation, especially as a particular child becomes more symptomatic and hospitalizations become more frequent and prolonged. As the number of infected children increases, we will have to look to other techniques to reduce burnout and depression among health care workers.

A Comprehensive Approach to the Problem

Owing to the unique problems presented to the medical community by the child with HIV infection, new approaches to the organization and execution of care have been attempted.
The Boston Comprehensive Pediatrics AIDS Program is the residential unit for infants and toddlers with HIV infection who cannot be cared for at home. The program functions within the Boston City Hospital grounds, with support from the Massachusetts Department of Public Health and the Boston Department of Health and Hospitals. It is set up as a home for these children until their parents are able to care for them or until other parenting arrangements can be made. It currently has a four-bed capacity, and, almost since the program opened in February 1987, there has been a waiting list for these beds. Respite workers provide direct child care on a twenty-four-hour basis. The philosophy of the program supports and facilitates the creation of a warm, caring environment. Through the combined efforts of a program coordinator, a social worker, a registered nurse, eight child health care workers, and volunteers, this program offers each child a specialized program for promoting maximum wellness. When it is appropriate, families are included in activities. Overnight visits, which allow the parents to learn to care for their child's special needs, may facilitate preparations for eventual discharge. This residential unit was developed for children who are medically stable and who need only “home medical care.” When a child has an acute problem for which she or he needs ongoing medical care, transfer to an inpatient ward is arranged. This separation allows for a normalization of life for children while they are in the residential facility.

Also at Boston City Hospital is housed Boston's only outpatient medical clinic designed to deliver multidisciplinary care to pediatric patients with HIV infection. Care is provided through a team approach, and staffing consists of infectious disease specialists as well as other subspecialty physicians. All children are followed with nutritional and developmental assessments. Social service and educational counseling are available to all patients as well. Communication with primary care physicians who have referred patients is maintained, and the program works in close association with the Boston City Hospital Adult AIDS Program, further establishing a family-based treatment program. The same team follows the patient and helps direct decision making when the child is admitted to the hospital, thus providing care of these families. In addition, all appropriate treatment protocols are made available to these patients and their families.

Control of the Epidemic

Currently, very exhaustive attempts are being made to develop a vaccine that will prevent HIV infection in individuals who have not yet been exposed. Numerous problems exist, making the search for an effective vaccine a very difficult one. The effort is complicated by the diversity of subtypes of the virus and by the lack of knowledge regarding the actual role of antibodies and cell-mediated immunity in the defense against HIV.

The objective of most investigators working on candidate vaccines is to develop a vaccine that will induce neutralizing antibody. It has been shown, however, that most patients with HIV infection have neutralizing antibody that is not effective in preventing AIDS. Direct cell-to-cell spread of virus may exist in conjunction with virus latency to "protect" HIV from the immune system. At the present time, it is not known how vaccination will effect either seronegative or seropositive donors. Animal testing is hampered by a shortage of chimpanzees; therefore, it will probably be necessary to test most vaccines in HIV-seronegative human volunteers.

We are a long way from being able to rely on a vaccine to control this epidemic, so other avenues must be explored.

Although universal blood screening of blood and blood products for HIV has not elimi-
nated the risk of transfusion-associated acquisition of HIV, it was an important step in decreasing the number of new cases. Because of the long latency period of the virus, however, new transfusion-related cases will continue to be diagnosed for some time.

Prevention of perinataly acquired disease will depend on the number of births to HIV-infected women. Efforts to identify and educate infected women who can transmit HIV to their children must be aggressive. Women who are at high risk must be counseled to undergo voluntary screening, and they must be educated about the risks associated with pregnancy in the seropositive mother. Of course, education must also focus on behavioral modification, including avoidance of high-risk sexual activities and of intravenous drug use.

Clearly, populations that are already at high risk must be counseled and educated. But the true spread of the AIDS epidemic will not be controlled until the general public is made aware of the risks. Containment of this disease will rest on our ability to effect changes in behavior and lifestyle so that the chain of transmission can be broken. The mass media, which often emphasize the sensational aspects of the AIDS epidemic, must educate the public so that fear does not spawn drastic policy measures that are unwarranted in terms of what is known about the actual risk.

Significant portions of the population, including intravenous drug users, adolescents, and persons with language barriers, are not being reached with the educational message conveyed through traditional media. The techniques of marketing research should be used to identify the most effective means of communicating with all segments of the population. Alternative communication resources should be explored. Only in this way can the stigmatization be reduced, thus allowing affected individuals to openly be counseled, tested, and provided with care. Without these measures, the number of HIV-infected adults, children, and infants will continue to grow to even more tragic proportions.

10. Personal communication from the Massachusetts Department of Public Health.

11. Ibid.


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**References**


Massachusetts Department of Public Health. Governor’s Task Force on AIDS. Policies and Recommendations (January 1987).


Glossary

ADCC. Antibody-dependent cell-mediated cytotoxicity.

Adjuvants. Materials used with vaccines to enhance the activity of a vaccine.

Cytotoxic (killer) T-cells. A component of the immune response involving a subgroup of lymphocytes that kill virus-infected cells.

Lymphokines. Chemicals produced by lymphocytes to communicate with other lymphocytes.

Transmucosally. Across mucous membranes such as those lining the vagina and rectum.

Virion. A single virus particle.