Social, Psychological, and Ethical Aspects of AIDS in Children

Graeme Hanson, MD

The virus that causes AIDS has made its devastation known in the child and adolescent population, although in relatively low numbers to date. Children are at risk for infection with the AIDS virus from three different sources. Very young children may have been exposed in utero or in the perinatal period from a mother carrying the virus. The school-age child may have been infected through transfusions of blood or blood products (for example, the child with hemophilia), and the teenager may be exposed through sexual activity or through sharing needles during I.V. drug use.

The increasing appearance of AIDS, AIDS Related Conditions (ARC), or the AIDS antibody in children confronts us with profound and difficult ethical issues. In addition, the potential is great for serious and long-lasting psychological consequences for the child, the family, and for society as a whole.

As the impact of AIDS on children becomes more apparent, at least three crucial needs can and often will conflict with each other: (1) the need for research to provide the knowledge and understanding of this disease in order to find an adequate treatment and cure; (2) the need for humane and sensitive treatment as well as protection for the individual child; and (3) the need to protect other people and to prevent the spread of the disease. When these needs conflict, there are no ready solutions. Nevertheless, in this emotionally-charged crisis we must be able to question and consider the results of our actions and the motivating factors behind them.

It is important to understand the powerful emotional responses that AIDS evokes in adults. These reactions result from the associations of AIDS with sexuality, homosexuality, illicit drug use, promiscuity, and prostitution. Each of these elicit strong societal condemnation, prejudice, and discrimination.

The power of fear and prejudice cannot be underestimated when we attempt to find a rational approach to this tragic condition. These feelings can affect not only the general public but also caregivers, service providers, public officials, and scientists.

“"AIDS hysteria" results from a complex combination of the usual fear of the mysterious and of the unknown and the very real consequences of AIDS. One aspect of fear and prejudice in these circumstances is the psychological need to segregate. In the AIDS context, this psychological need becomes intricately interwoven with real threats of contagion and the uncertainties about the spread of the disease.

Questions of Confidentiality

Due to the intense emotional climate surrounding the AIDS epidemic, one of the most important issues for the child with AIDS, ARC, or confirmed exposure is the matter of confidentiality. Questions immediately arise: Who needs to know? Who needs to know what? And for what purpose? These are questions that must be faced.

Does the potential good of revealing this information outweigh the potential harm and how can the confidentiality be ensured? Who controls this information? Opinions vary greatly on these matters; different jurisdictions are already enacting very different kinds of regulations for reporting, dissemination of information, and quarantine options. (A public opinion poll conducted last December by the Los Angeles Times regarding AIDS in adults found that 48 percent favored mandatory identification cards for people with positive results to the AIDS antibody test. Fifty-one percent supported quarantine, 15 percent supported tattooing people with AIDS. Interestingly, 55 percent said they would send their child to a classroom even if a classmate had AIDS.)

Vaccines and Foster Homes

For the infant and very young child infected with the virus and showing AIDS-related symptoms, there are certain important precautions necessary for the protection of the child.

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The young child with AIDS or ARC probably should not be immunized with live virus as is found in mumps, measles, and some polio immunizations. Therefore, the caretakers of these children need to protect them as much as possible from exposure to live virus, especially to certain childhood diseases like chickenpox, mumps, and measles. The primary caretaker and the physician of the child need to know if the child is immuno-compromised; the caretaker should understand that a child can be seropositive and still be clinically healthy.

The situation becomes complicated if one considers that many of the babies with AIDS or ARC symptoms or with seropositivity are born to drug-addicted mothers and are likely to be placed in foster care. Therefore, the foster parents will need to know. In those cases how many foster parents will want to care for such children? What impact will this have on the foster care system already significantly lacking in adequate foster homes? If the child develops AIDS while in foster care, the likelihood of that child being returned to the system is great, creating yet another trauma for an already vulnerable and compromised child.

Social and Psychological Implications

For the seropositive young child living with his or her natural parents, the parents will live with a painful uncertainty. How will this affect the parents' relationship with their child? If the child develops AIDS, the parents and especially the mother may be overwhelmed by a sense of guilt for having infected the child.

For the school-age child, the social implications of having AIDS, ARC, or seropositivity are of special significance. This is an age when being able to attend school, to participate in activities with other children, to be acceptable and be included in a group are very important. If children are excluded from school or from certain activities, they will likely experience serious psychological and social adjustment difficulties.

Medical experts generally recommend that children with AIDS be allowed to attend school. If the condition of these children becomes known to their classmates, they will likely be subject to teasing and discrimination. If these affected children are excluded from school or from other activities, they will most likely be encouraged to keep confidential the reason for their exclusion. Having to keep this kind of secret can have detrimental results in the development of a positive sense of self, of being acceptable, and of being integrated. These children and their parents will need help in adjusting to this situation. Parents will especially need advice and counseling regarding how they can discuss this complex matter with their child.

Teenagers are at risk for AIDS through sexual activity and through sharing needles during I.V. drug use. The question of screening at-risk teens is a difficult one. If the information obtained by such a screening would be clinically useful, then screening might be advisable. At present the disadvantages appear to outweigh the advantages. This is especially true for those teens who are probably the most at risk, the homeless runaways who are vulnerable to drug use and prostitution.

Many of the issues that apply to school-age children also apply to teenagers, such as the problem of being excluded, of being handicapped, and of being socially isolated. In addition, many of the social and psychological factors that affect adults also affect teenagers. If a teen is seropositive and the family is informed, educated guesses about the teen's sexual life or drug use could result in additional psychological trauma for both the teenager and the family.

Teenagers are becoming more aware of and frightened by AIDS. Recently a 16-year-old boy became panic-stricken after kissing a new girlfriend. He had had some homosexual experiences in the past few months, and suddenly he began to worry that he might be infected and might have infected his girlfriend.

Homeless and runaway youth are especially vulnerable to exposure. They particularly need education and supportive counseling regarding sexual practices and drug use. At the same time, because of their lifestyle, they may be extremely difficult to reach.

Explain the meaning of a positive AIDS antibody test to a teenager could be a very complicated undertaking. The ambiguity and uncertainty may be more than the teen can tolerate. Under such circumstances teenagers tend to act out: the possibility of behavior disturbance, flight into promiscuity, and suicidal activity is great.

Another aspect of AIDS in teens is the unfortunate and painful discrimination that a teen with AIDS may experience from peers. Teenagers frequently struggle with their sexual identity, and prejudice against homosexuality can be profound in this age group. A teenager who has AIDS, ARC, or is seropositive may be seen as tainted or somehow associated with homosexuality in the other healthy teenagers' minds, and they may thus face discrimination.

"Efforts to educate the public are critically important; they must be more intensive than might be needed in a medical crisis without such complex psychological and social overtones."

Recommendations

At this point a few recommendations are pertinent. We need to keep the social and psychological implications clearly in mind when developing public policies. The discussion of school admissions must occur with knowledge of the possible psychological effects on children. Infants of mothers-at-risk for AIDS may need to be tested for presence of the AIDS antibody to protect those who are seropositive and immuno-compromised from possibly harmful immunizations with live virus.

We will need to provide skilled and trained counselors to help both the children and their families to understand and adjust. All people in the position of caring for children will need education and support, especially teenagers, foster parents, and childcare workers. Parents whose children are in contact with children with AIDS will need information and advice. Most importantly, children themselves will need information and education. Accurate information and understanding are our best tools at this point to help lessen the psychological and social trauma for children with AIDS, ARC, or exposure to the AIDS virus.

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Pediatric AIDS: The Scope of the Problem

Michael Helquist

Although the Centers for Disease Control (CDC) note a total of 217 cases of reported pediatric AIDS as of December 1, 1985, physicians who treat infants and children with AIDS estimate that the actual number may be two to four times that tally. Dr. Arye Rubinstein, a professor of pediatrics at New York's Albert Einstein College of Medicine, told a special childhood immunodeficiencies symposium last year that he believed the number of pediatric AIDS cases is lagging from one to two years behind adult AIDS. Rubinstein noted that the AIDS retrovirus is first transmitted and incubated in adults before being passed on to infants.
The majority of pediatric AIDS cases in the United States are seen in New York, New Jersey, Florida, and California — with other major cities, such as Chicago, St. Louis, and Dallas, seeing an increasing number of cases. Most of the children were exposed to the AIDS virus by their at-risk mothers during pregnancy and birth. Although 40% of the AIDS cases in the United States are among non-white adults, a significant 80% of the pediatric AIDS cases occur among non-white infants and children.

James Oleske, MD, a professor of pediatrics at the University of Medicine and Dentistry of New Jersey in Newark, estimated that as many as 1,000 children nationwide now experience symptoms of AIDS that have gone unrecognized and unreported. Although pediatric AIDS can be distinguished from other childhood immunodeficiencies, some of the symptoms, such as diarrhea and swollen lymph glands, are present with several other diseases and thus make accurate diagnoses difficult. To help clarify the actual incidence and natural history of pediatric AIDS, Arthur J. Amman, MD, director of immunopharmacology at Genentech Inc., proposed that the CDC case definition for pediatric AIDS be expanded. Amman suggested that the definition should encompass epidemiological data, clinical evaluation, immunologic studies, viral isolation, and the detection of antibodies to the AIDS retrovirus to establish firm evidence of the disorder (Ann Intern Med 1985: 103:734-737). Amman advised that a pediatrician who believes a patient has the syndrome should refer the child to the medical center personnel who are skilled in pediatric immunology.

Pediatric AIDS patients also present with recurrent thrush, bacterial sepsis, and lymphoid interstitial pneumonia, a condition so common that the CDC added it to the definition of pediatric AIDS. In addition, the involvement of the brain as found in adults also occurs among 40 to 50% of infants and children with AIDS. Experts judge the mortality rate of pediatric AIDS is at least 50%, climbing to 75% if an opportunistic infection is present. The response to therapies in the pediatric population is discouraging. At the same time, a number of children infected with the virus and with immunologic abnormalities are reported to be clinically well.

During a recent Congressional subcommittee hearing, Morton J. Cowan, MD, of the UC San Francisco Department of Pediatrics, testified that about 10% of drug-abusing mothers and their offspring at San Francisco General Hospital have evidence of infection with the AIDS virus. Cowan estimated that with 150 of these women delivering babies at the hospital each year, about 15 new cases of pediatric AIDS can be expected annually. Due to the problems with placement and care, for these infants must often remain in hospitals. Their care quickly becomes very expensive.

MMWR Guidelines
In the August 30, 1985 issue of Morbidity and Mortality Weekly Report, the CDC offered guidelines to help state and local health departments establish policies for children known to be infected with the AIDS virus. The federal agency advised that children with an AIDS viral infection should be admitted to schools based on the behavior, neurologic development, and physical condition of the child. Children who lack control of bodily secretions or who have uncoverable oozing lesions should be placed in a more restrictive environment. Caretakers of children with AIDS should employ in-home infection control guidelines, avoiding direct contact with bodily fluids. While the CDC does not advocate mandatory screening of all children as a condition for school admission, the agency does suggest that adoption and foster care agencies should add AIDS antibody testing for full medical evaluations. [Note: In California such testing has not been mandated; current state laws related to AIDS antibody testing and confidentiality extend to children as well as adults.]

CDC officials concluded that all public health departments and educational agencies should inform parents, children, and educators about the AIDS virus and its transmission.
BRIEFS

IN REVIEW

UNDERSTANDING AIDS: A Comprehensive Guide. Victor Gong, MD, editor. Rutgers University Press, New Brunswick, New Jersey, 1985; 240 pages, paperback. The twenty contributors to this volume draw from a wide range of experience in medicine, epidemiology, nursing, psychology, immunology, microbiology, social work, and social interaction with the gay community. The several chapters offer extensive reviews of current knowledge about the care and treatment of people with AIDS as well as sensitive discussion of the ethical and moral issues that continue to overshadow the AIDS epidemic. While no book on AIDS can keep up with the almost weekly reports of new research, this volume provides a sound basis and a context for understanding research advances.

Psychosocial responses to AIDS receive only a cursory review here, and mental health professionals might wish for a more balanced and informative discussion of such pertinent matters as what people with AIDS cope with issues such as responsibilities, guilt, sexuality, and sexual expression after diagnosis. Political and legal implications of the AIDS epidemic are not addressed at all. In general, however, this book provides the layperson with one of the best presentations of the medical and scientific aspects of AIDS now in print.

RECENT REPORTS

Disabling Fear of AIDS Responds to Antidepressant. A recent case report in the journal Psychosomatics (February 1986) details the effective treatment of excessive worry about contracting AIDS with the antidepressant drug Imipramine. A 40-year old successful businessman developed such a fear of AIDS that he was ready to quit his job and make "worrying about AIDS a full-time career." After daily administration of 100 mg/d of Imipramine for one month, his fears were completely resolved. Authors Michael A. Henike, MD and Carlos Pao, MD suggest that patients who appear overcome with fear of AIDS in the absence of physical disease may be served better by a trial of antidepressants than by a series of expensive tests.

AIDS Patients Want To Discuss Life Sustaining Care. A large percentage of gay men with AIDS want to discuss with their physicians life sustaining treatment, but few of the patients have done so, according to a study published in the New England Journal of Medicine (February 13, 1986). Perhaps as a result of this lack of discussion, many of the 118 San Francisco men with AIDS in the study believed life sustaining treatments might be more effective than they actually are. Bernard Lo, MD, and his colleagues at UC San Francisco who conducted the survey, concluded that repeated discussion with patients, beginning in the outpatient setting, was needed. Other findings from the study revealed that most of the patients had already thought about life sustaining treatments, more than half wanted intensive care and a mechanical respirator if they could no longer breathe on their own, and nearly half wanted to be resuscitated if their hearts stopped. Although nearly half wanted their partners or friends to be substitute decision makers if they became incompetent, only 42% of these men had completed "durable powers of attorney" for health care. This legal option allows the patient to designate a proxy to make decisions about medical care if the patient should become incompetent. The UCSF researchers noted, "Without it (durable powers of attorney), partners and friends have no legal standing to share decisions with physicians." Lo suggested that these legal and treatment decisions should be made by patients, and that physicians should raise the issues with patients before they become too sick or mentally incompetent.

Possible Heterosexual Spread of AIDS Indicated. Results from a study conducted by the University of California Berkeley and the San Francisco Department of Public Health provide additional evidence that the AIDS virus may be transmitted from men to women through vaginal intercourse. More than ten percent of 60 women who had sex with men infected with the AIDS virus later showed signs of exposure themselves. None of the women exposed to the virus has developed any of the diseases or conditions related to AIDS. In addition, the preliminary results, according to epidemiologist Nancy Padian, do not indicate how easily AIDS might spread among the heterosexual population.

Only one of the women whose blood revealed antibodies to the AIDS virus recalled any possible exposure other than vaginal intercourse with a man who later developed AIDS or who was found to carry antibodies to the virus. The woman reported possible exposure from both anal and vaginal intercourse.

Two other studies, one from Boston researchers and the other from San Francisco scientists, revealed that the AIDS virus had been found in vaginal and cervical secretions of 21 women who had multiple sexual contacts with either bisexual men or with needle-sharing intravenous drug users. The finding confirms that the virus can be present in yet another bodily fluid, female genital secretions, and further suggests that men can contract AIDS through intercourse with a woman infected with the virus. However, as in the case of the AIDS virus being found in tears and saliva, the transmission of the virus via some bodily fluids is not supported by epidemiological findings.

Researchers from both studies asserted that it was too early to draw any conclusions about female to male transmission.

The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. This newsletter represents an attempt to place much of the data and press reports in a context that will prove meaningful and useful to its readers. Suggestions and comments are welcome and encouraged. Please address correspondence to Editor, AIDS Health Project; 333 Valencia Street, 4th Floor; San Francisco, CA 94103. For information about other AIDS Health Project programs, call (415) 626-6637.

NEXT MONTH

Mental health professionals report an increasing number of requests from their AIDS and ARC clients for information about pain management. Not only those presently experiencing pain but also those clients who fear the development of painful physical conditions want to know what medications and therapies are available.

In the May issue of FOCUS, Robert Brody, MD, Assistant Clinical Professor of Medicine at San Francisco General Hospital and medical consultant for hospice services, will consider the control of pain in people with AIDS and ARC, particularly those at the latter stages of the disease. Brody will discuss the role of anxiety and the fear of abandonment in the experience of pain; he will also suggest specific regimens and medications for specific symptoms. Finally Brody will suggest how to assess the patient with "questionable pain."