The Impact of HIV Infection on Childhood Health Programs

William A. Smith, EdD and Gary B. MacDonald

To date HIV has struck mostly young, well-educated, and productive adults who form the backbone of society’s effort to achieve economic and social progress. Programs designed to slow the spread of HIV infection among this primary age group have begun to divert scarce resources from fragile health systems that attempt to meet the needs of the total population.

In many countries, especially in the developing world, child survival programs have had the priority for the last few decades. Obviously, if children do not survive, prospects for the future are diminished. However, these child health programs may be the first to suffer once health officials feel forced to reevaluate health priorities in view of the increasing demands from AIDS prevention and care programs.

Epidemiologists project as much as a tenfold increase worldwide in the number of diagnosed cases of AIDS in the next few years. Children will comprise an increasing percentage of these cases and of those infected with HIV. While the United States and other developed countries face mounting numbers of cases, many developing countries confront even greater numbers of cases due to the predominant heterosexual transmission of HIV among their populations.

These projections must be understood within the context of other equally grim estimates. A significant number of children die of many other diseases each year, including diarrhea, whooping cough, measles, tetanus, pneumonia, malaria, and malnutrition. Among these other threats, HIV infection is not unique in its capacity to divert limited health resource “pie” to too small.

Child Mortality

From the beginning children have been dying from AIDS and ARC. This situation has been true in developing countries as well as in industrialized nations. Infants are primarily infected with HIV either in utero, at birth in the course of passing through the birth canal, shortly after birth by means of breast-feeding, or as a result of a contaminated blood transfusion.

The prognosis for HIV-infected children is not good. At present, studies indicate that a higher percentage of HIV-infected children will present with clinical symptoms, and they do so more quickly than adults. This more rapid onset of disease may be due to the child's immature immune system or to other factors that are not well understood. As many as 40% of these children will become ill within the first year or two of life. In many developing countries this number equals the percentage by which health officials had hoped to reduce their infant mortality. This fact alone suggests that HIV and AIDS have the capacity to cancel the gains in childhood health and survival that many countries have worked so hard to achieve.

Four key interventions — programs in diarrheal disease control, immunization, infant and maternal nutrition, and family planning — have offered hope for reducing child mortality even in the world’s poorest countries. Now that hope is severely challenged by the advent of HIV.

HIV and Diarrheal Disease

The thrust of diarrheal disease control in the developing world has been toward oral rehydration therapy (ORT) and away from the more expensive and riskier intravenous (IV) therapy. The vast majority of children with mild diarrhea do well on ORT and do not require IV treatment, which is an advantage given the potential dangers of the latter for transmission of HIV.

In addition, blood transfusions are still occasionally used for purposes of rehydration in the IV treatment of diarrhea. Because of the resource allocation problems outlined above, many developing countries have not yet begun the systematic screening of their blood supplies for HIV contamination. Thus, the use of unscreened blood transfusions for any therapeutic purpose carries with it the strong possibility of HIV transmission. The threat of HIV infection may actually serve to increase use of ORT by stressing its advantages in promoting child survival over potentially more dangerous therapies that involve the use of needles.

continued on page 2
Childhood Health . . .

continued from cover

HIV and Child Immunization

The danger of HIV and AIDS to child immunization programs is a matter of the misuse of unsterile needles and the perception that immunizations may spread HIV. For example, if a child remains unimmunized because the parents fear the immunization will also infect the child with HIV, the child faces a much greater risk of dying from diseases other than AIDS. Stated another way, the excessive fear of immunizations because of their link with HIV could cause many more deaths than improper immunizations themselves.

In the developing world there remains, however, a significant risk for HIV infections through the use of unsterile needles for purposes of routine injections, immunizations, and scarification. [Editor’s Note: Scarification is a practice of inflicting wounds, usually on the face, as a mark of beauty]. Health professionals will need to be vigilant in their efforts to eliminate all uses of unsterilized needles for any purpose whatsoever.

An increasingly important question in the health care management of HIV-infected children will be the effect on them, if any, of individual immunizations. Research to date suggests that live virus vaccines are safe when administered to HIV-infected children, although vaccine efficacy may be lower in some of these children due to their compromised immune systems.

HIV and Child Nutrition

Researchers have documented only three cases of breast milk-related HIV transmission. Because the benefits of breast-feeding far outweigh the risk of HIV infection, breast-feeding should still be encouraged. The Special Programme on AIDS of the World Health Organization offered this same advice earlier this year.

There are potentially troublesome aspects to maintaining sound, overall child nutrition. Children have been known to live several years after infection with HIV, although over time they may sustain considerable weight loss. Under other circumstances that weight might be restored with careful nutritional management. However, it is unclear that HIV- or AIDS-related weight loss in children can be reversed. Conversely, failure to thrive in children in whom HIV infection has not been established may well be related to HIV and constitute, in fact, the first clinical indication that HIV is present.

HIV and Family Planning

HIV prevention programs have several features in common with established family planning efforts, and a complementary relationship could result from an integrated approach to serve both program objectives.

The most fundamental similarity between AIDS and family planning is that both programs focus primarily on sexual behavior. In practice this means that programs must cope with the following realities:

(a) The major target group is young sexually active adults aged 14 to 35. This is an age when sexual activity is very important, is based on strong biological urges, is closely linked to self-image and self-esteem, and is therefore extraordinarily difficult to change.

(b) The subject is taboo in many societies. Accurate and complete communication and sympathetic provision of needed services face may social constraints.

(c) The services provided aim more at preventing an undesirable result than promoting a favorable one. The major actions that family planning and AIDS prevention programs recommend are using condoms, other safer sex practices, or abstinence. These are not messages or behaviors that most clients will welcome readily.

(d) Both programs involve the behavior of a couple rather than an individual. The desired practices may depend not on just one individual’s willingness to change behavior but also on the willingness of a sexual partner.

(e) Both family planning and AIDS prevention are concerned with long-term consequences not immediate results and with probabilities not certainties. Immediate and certain sexual pleasure must be weighed against possible adverse effects in the future.

Planners of HIV prevention programs can learn important lessons from family planning health educators who have developed interventions to cope with the possible difficulties listed above. These include effective use of counseling, offering choices to clients, innovative promotion of sex education, social marketing of condoms, and community-based distribution of products and services.

Planners of child health programs may be reluctant to consider how HIV prevention can augment and support their efforts. In the case of family planning especially, health workers may fear possible adverse consequences by linking family planning and AIDS prevention in the minds of target populations. They may not want to associate family planning services with a fatal disease. They may also fear that condoms—which are not the most effective method of family planning—will displace more effective methods, such as voluntary sterilization, IUDs, or oral contraceptives. The result could be that women not at great risk for AIDS could increase their risk of unwanted pregnancy.

Family planners may also question whether the image of their work as a family-oriented service may suffer given that AIDS is associated in the minds of many with multiple sexual partners and homosexuality.

Complementary Goals

It is also important to note the ways in which the advent of HIV may actually augment and improve child health in the developing world. It will do so partly by attracting new human and financial resources, which, with proper planning, may be shared among a variety of programs. It will broaden awareness of reproductive and child health issues generally and will encourage the behavior changes that ultimately will assist children as well as adults to live longer and healthier lives. HIV-related programs may also lead to a greater acceptance of health education and sex education.

More specifically, the development of AIDS testing capabilities may strengthen basic laboratory services while the training of health care personnel to advise prospective mothers about AIDS may lead to better general care for mothers and infants.

Summary

There is no doubt that AIDS and HIV prevention programs will have a significant impact on all health promotion efforts in all countries. What remains less certain is whether health planners and government officials will find the means to address the problem of HIV transmission without subverting existing programs that are crucial to the health of their populations. In the case of childhood health programs the challenge will be to recognize and implement interventions that serve the goals of both AIDS prevention and child health. It is already apparent that such efforts will require international cooperation and financial assistance from the developed world to developing nations.

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Diagnosis/Treatment/Prevention
Psychological Support for Children with AIDS

Lew Katoff, PhD

Pediatric AIDS is a horrifying and devastating disease. Since 1982, more than 500 pediatric cases of AIDS in the United States have been reported to the Centers for Disease Control (CDC), although this statistic is not an accurate reflection of the entire epidemic. Public health officials in high incidence areas estimate that there are at least four times as many children with life-threatening HIV infection as diagnosed cases. The majority of psychological support to these children and their families is a difficult, yet ultimately rewarding task.

The Emotional Impact

The problems for children with AIDS and their families are pervasive and unending as illness leaves them increasingly dependent and vulnerable. These children are passive recipients of care which is usually not quite enough to comfort or ease the pain. Depression may occur in the face of separations, erratic caretaking, and changes in routine brought about by frequent and protracted hospitalization.

The emotional resources of the family may be drained by the grief experienced by parents and siblings and the guilt frequently expressed by HIV positive parents. The parents may simultaneously blame themselves and rage at a hostile world. In addition, the social stigma of AIDS and irrational fears of contagion can lead to isolation of the family at a time when the need for support is greatest. The child's diagnosis may be a family secret because they fear being ostracized or harassed. A child with AIDS sometimes will be difficult to care for, and a mother's confidence in her parenting ability may be compromised. Further, many families of children with AIDS live in inadequate housing and lack financial resources and access to potential community services. The disease process and its complications may be incomprehensible, and the likely outcome is impossible for parents and relatives to accept.

Problems with Service Delivery

Continuous and coordinated medical treatment is provided to only a small percentage of cases because different bureaucracies and institutions address the social, health, and environmental needs of these children and their families. There is rarely a successful effort to insure all services needed by the family are available. When the family cannot provide necessary caretaking, intermediate care facilities and alternate placement options prepared to care for families are limited or non-existent. Finally, there is an insufficient number of foster homes, a lack of child welfare policies which address the issue of HIV infection, and restricted access to day care.

GMHC's Pediatric Services

In 1981 the Gay Men's Health Crisis (GMHC) began addressing the needs of adults with AIDS in New York City. Staff and volunteers provide support services to people with AIDS who are having difficulties dealing effectively with the social, behavioral, and emotional consequences of their illness. Volunteers establish an ongoing, accepting relationship with clients and provide support and encouragement. They provide clients with needed information and referrals, peer counseling, and help with daily living activities. Volunteers give four to eight hours each week to their assigned clients, and each receives weekly supervision by team leaders and staff. Charts are monitored by staff and by the agency's Quality Assurance Committee.

In the fall of 1985, GMHC received its first pediatric referral, a child who had been hospitalized for an extended period of time. A volunteer provided companionship during the hospitalization and identified needed resources and equipment when the child was able to go home. Beginning in December of that year, volunteers specifically interested in pediatrics were recruited. To date GMHC has provided services to 35 children, ranging in age from six months to eight years.

Pediatric volunteers address both the psychological and social needs of the child and family. The volunteer is a source of affection — someone who holds, listens, and entertains the child. Volunteers encourage stimulation of intellectual and language skills. Depending on the need of the child and the family, the volunteer may also fulfill the role of a big brother or sister, an advocate, or a peer counselor.

Volunteers also provide emotional support to family members. The volunteer listens to concerns of parents, and, when appropriate, encourages their expression of fears, frustration, and sadness. Many volunteers cope with the families' feelings of denial, which is handled gently and respectfully. The volunteer may be an accepting sounding board for parents who cannot comprehend the problems that beset them. Volunteers also provide concrete services, including household tasks and "baby-sitting," to provide a respite for caregivers.

At this time, the most significant obstacle in the development of pediatric volunteer services in New York is geographic. The involved hospitals and families are located in communities physically and culturally distant from the communities that provide volunteers. More specifically, many of the children are blacks and Hispanics while a majority of the volunteers are gay, white men.

GMHC's Financial Advocacy Program assists clients through the maze of government agencies and benefits, including social security, medicare, and welfare. The volunteer can help by monitoring these entitlements and by advocating when problems occur. The volunteer assists with applications for entitlement programs and housing. Volunteers can assist in informing parents about nutrition, infection control, child development, and developing support systems. The program is interested particularly in advocating for appropriate placement in early intervention, preschool, and school programs.

Confidentiality is a priority in the provision of services. Volunteers are reminded constantly of the importance of maintaining the confidentiality of clients. With informed and written consent, contact is established with the health care and social service agencies involved with the child. A volunteer sometimes can be a liaison or an extra set of legs for a social worker. Volunteers can assist in facilitating compliance with medical procedures (for example, arranging transportation to appointments).

Recommendations

In addition to the services above, a social service program for children with AIDS-related illness must also address advocacy and public policy issues. A community-based organization serving this group must establish liaison with pediatric and social service providers to learn about existing services. Particular attention should be focused on (1) the administrative and program procedures of child welfare agencies; (2) access to day care and educational programs; (3) the availability of comprehensive and continuous medical services; and (4) community education about HIV infection.

Lew Katoff, PhD, the Director of Client Services for GMHC, oversees the delivery of group, financial advocacy, and legal services to 1,600 clients. Formerly the Coordinator of Crisis Intervention Services, Dr. Katoff helped develop GMHC's pediatric program.
BRIEFS

In Review

Questions & Answers on AIDS. Lyn Frumkin, MD and John Leonard, MD. Avon Books, New York, NY, 1987; 150 pages, paperback, $3.95 US.

An increasing number of AIDS-related titles appear on the shelves of bookstores around the world; few have been comprehensive as well as accessible for the general public, health care workers, and informed health consumers. This newly published volume proves to be the exception. It employs a question-and-answer format while it maintains a narrative style; the combination provides the reader with a great amount of information in segments that are easy to digest. At the same time, the authors refrain from simplistic answers; rather they bring the readers along with them, explaining medical terms as they proceed.

This volume, much more so than others published during recent years, should be helpful especially to AIDS educators and health workers as they prepare for presentations to a wide variety of audiences. All major concerns about AIDS and HIV infection — including medical, epidemiologic, social, legal, and psychological — are covered extensively here.

The authors could improve future editions with a more thoughtful look at who is at risk for HIV infection, focusing more on risk behaviors than risk group membership. In addition, the authors pose questions about the licensing of experimental drugs and the adequacy of government funding for AIDS research, but their responses are so limited as to suggest a lack of understanding of the historical and political issues involved. The volume unfortunately fails to credit the several years work of community-based AIDS organizations for the current foundation of AIDS education materials and services.

Even with the limitations mentioned above, this is a comprehensive and valuable addition to the literature about AIDS, one that most segments of society and most professions will find useful.

Reviewed by the editor of FOCUS, Michael Heltquist, who recently accepted a position in Washington D.C. as Program Officer-Information for AIDSCOM, a U.S. AIDS prevention project directed to developing countries. He will continue in his role as editor.

Recent Reports

New Antigen Test May Aid Screening, Diagnosis, and Treatment. A new enzyme immunoassay can detect the core protein of HIV, thus yielding information with important implications for screening blood, treating patients, and developing vaccines. The current HIV antibody test reveals only the presence or absence of antibodies to HIV, indirectly suggesting the virus is present in those who are seropositive. In addition, detectable antibody responses often occur only several weeks after the primary infection; and in infants of 15 months of age or less, the transfer of maternal antibodies precludes detection of the infant's serologic status.

The new test, according to U.S. researchers, is simple, cost effective, more sensitive, and faster than existing viral detection tests. The new method reveals the presence of the virus (HIV) before antibodies develop; as such, it may be useful in screening blood donors and determining the presence of the virus in the newly infected, including infants. In addition, the detection of HIV core antigen by these methods may help in monitoring patients for progression of disease and for response to antiviral therapy. The new test may serve also as an infection marker in future trials of potential vaccines. This report was published in the September 1987 issue of Annals of Internal Medicine.

Foster Care Needs of Children with HIV Infection. Children with perinatally acquired HIV infection often are members of families with multiple problems, according to health care providers at the Children's Hospital of New Jersey and the New Jersey Medical School in Newark. In a study of 50 families with 57 HIV-infected children, 17.5 (42%) of the families had already been referred to the local family protective agency — before a diagnosis of HIV in the children — for such reasons as neglect, abuse, and foster care placement. Nearly half of the children were referred to foster care because of the death of a partner, illness of a parent, and inability or unwillingness of the parent to care for the child. All foster care placements were maintained with extensive support to the foster family, especially after the diagnosis of HIV infection in the child. The health care workers in New Jersey reported that extended foster family members require extensive education about AIDS as well as ongoing social and financial support if the placement is to be successful. This report was presented at the Third International Conference on AIDS in Washington, D.C. in June of this year.

Next Month

Health care providers have an excellent opportunity to educate and counsel their clients and patients about AIDS prevention. Yet many professionals remain reluctant to initiate discussions about sexual activities — an absolute necessity if effective HIV risk reduction counseling is to occur. In the December issue of FOCUS, Michael Shernoff, CSW, ACSW will provide an analysis of how health care professionals can integrate AIDS prevention counseling into their clinical practice. Shernoff is the Co-Director of Chelsea Psychotherapy Associates in New York City.

Also in the December issue, Sandra Jacoby Klein, MFT and William Fletcher III, LCSW will discuss the emotional, social, and education needs of individuals who are caretakers of people with AIDS. Klein, a Los Angeles therapist who specializes in the emotional effects of illness, and Fletcher, Acting Director of the Hospice at West Los Angeles, VA Medical Center, will also consider the supportive interventions they have found helpful for both patients and caregivers.

FOCUS A GUIDE TO AIDS RESEARCH

SUBSCRIPTIONS/CORRESPONDENCE

The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. The goal of FOCUS is to place the data and medical reports in a context that is meaningful and useful to its readers.

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