The child with HIV disease is often the index case of the family unit, leading to the identification of infected parents and siblings previously considered healthy.
As women infected with HIV become ill and die, we will be confronted with many orphaned children, both infected and uninfected, and must begin to plan for their needs.

Perinatal infection. Even before the emergence of HIV, the economic, educational, and social opportunities for children born into inner city communities were sharply curtailed. Infection with HIV must be interpreted in the context of the many other social issues affecting these children's lives.

**HIV INFECTION: A FAMILY DISEASE**

Human immunodeficiency virus infection affects the entire family. Experience teaches us that the mother may not be able to remain an active participant in the child's care and nurturing. We are forced to examine long held assumptions about the care of ill children and to look for feasible, creative alternatives.

At Columbia University's Harlem Hospital Center, in New York City, over 200 children have been identified as HIV antibody positive or infected since 1985; 71% of their mothers gave a history of intravenous drug use (IVDU); 19% identified an IVDU partner. Only 46% of the children have been able to remain with a natural parent. In our experience, women who are actively using drugs are unable to provide for the complex needs of an HIV-infected child. Medication schedules, frequent treatment visits, and a high level of organized contact with the medical community conflict with the social and financial burdens of drug use. A small number of women, overwhelmed by guilt, despair, or the need to attain drugs have abandoned their children. Women seeking drug treatment are often thwarted by the unavailability of programs. Treatment programs make few accommodations for women with children; inpatient and outpatient programs rarely provide child care or a family-oriented approach to rehabilitation. Many of the children born to drug-using women must be cared for in an alternative setting.

HIV-infected women also face their own morbidity and mortality. Many women neglect their own health, focusing on the care of their infected child. Other women, already quite disenfranchised, are distrustful of the medical community, viewing it as still another fearsome bureaucratic institution. They often find the battery of appointments, diagnostic tests, and daily medications in conflict with the pace and level of organization to which they are accustomed. For all infected women, independent of socioeconomic status or risk factor, the medical manifestations of HIV infection may ultimately impair their ability to care for their children. Ultimately, maternal and paternal death will result in the need to find long-term care for the children.

Extended family members suffer the ramifications of HIV infection as well. Uninfected siblings, some already suffering the effects of intrauterine alcohol and drug exposure, are left to witness the consequences of the infection. While parents struggle to cope with their disease, these children must cope with the loss of their mothers and siblings. Parents, trying to spare pain, may keep their children uninformed about their own illness. At the same time, older siblings are often intimately involved in the care of both the ill child and the ill parent. Confused and frightened, these children are lost in the shuffle, as the medical community focuses on the infected individuals. The overwhelming long-term psychological and social consequences of HIV infection for these children cannot be underestimated. In time, these survivors will require a new home and a new family, if they are to overcome these losses.

Extended family members, aunts, uncles, and especially grandparents have become increasingly important in the provision of care for HIV-infected children; 27% of the children followed at our center reside with an extended family member. Children may be removed from the natural parent by child-protection agencies and officially placed with a relative. The grandmothers and aunts frequently assume care for many grandchildren, including those with HIV infection. For the grandmothers, ailing health, limited financial resources, and multiple responsibilities can further complicate the medical management of a sick child.

**ALTERNATE CARE AND AUGMENTED RESOURCES**

In 1986 and 1987, few alternatives existed for the care of HIV antibody-positive children outside of the natural household. Little attention was paid to the many children who were living in hospitals while medically ready for discharge. The social service community had not acknowledged that the placement of HIV-positive children posed a new challenge requiring special attention and resources. Although the problem was concentrated in New York and New Jersey, the issue was beginning to surface nationally. HIV-infected children were living, sometimes their entire lives, in hospital wards for lack of more appropriate settings.

In response to the special needs of these children, several options have been developed. Although the continued on page 485
details vary in each state, resources have been developed to recruit foster care families willing to care for children at risk for HIV infection. These families require ongoing training and support as well as additional resources. Individual foster care agencies offer programs such as support groups for foster parents, nursing and homemaking services, and ongoing training. Some states offer higher stipends to families caring for infected children. In some states, these programs are now available to extended family members caring for HIV-infected children as kinship foster homes.

Several transitional care units for HIV antibody-positive children have been opened and others are in the planning stage. These centers, including Saint Clare's in New Jersey and Incarnation Children's Center in New York City, function as transitional care facilities for children awaiting foster care placement. These units have been developed with the goal of offering a nurturing, normalized environment to HIV antibody-positive and infected children. Children in New York City now leave the hospital when medically ready and remain at Incarnation Center until an appropriate foster home is identified.

As the number of infected children continues to rise, the need for alternate care facilities will also increase. Relatively few women with AIDS have been identified, but many are known to be infected. As these women become ill and die, we will be confronted with many orphaned children, both infected and uninfected, and must begin to plan for their needs. They will require appropriate, nurturing homes, as well as ongoing medical and psychological support. If possible, the natural families should participate in decisions about the futures of these children. This requires the availability of resources, a coherent and accessible social service organization, as well as a direct and open relationship between the family and providers. Besieged by a lack of resources and the difficulty of discussing issues about death and dying, the health care team often focuses entirely on the concrete medical issues, neglecting these more delicate and difficult problems. It falls to the pediatric provider to act as an advocate for these children, to openly involve the families in planning for the children's future, and to delineate identified needs to the social service sector of our communities. These children cannot speak for themselves.

Home-based, hospice, and respite care services must be developed. Home-based services including nursing, occupational and physical therapy, household assistance, and special transportation vary in availability from state to state. Hospice and respite care facilities for children and families are being planned in a number of areas, but no such facilities presently exist. Despite advances in the field, many children reach the stage of disease when supportive care is appropriate until death. Some families have decided to keep their children at home, but many children have no option but to linger until death in hospital wards.

ADVOCATES AND CONSENT

Traditionally, parents speak for their children; they are given ultimate responsibility about the course of care, treatment options and protocols, as well as antibody testing. The dissolution or unavailability of the natural family for many children with HIV infection has again caused us to reevaluate assumptions about who can represent the children. In the past, the majority of cases have been handled on an individual basis. We are now confronted with legions of parentless children, each facing a lifetime of complex medical, legal, and social decisions.

Consent is routinely obtained for common medical procedures, including blood transfusions and radiologic evaluations. Consent is necessary for any child to be enrolled in a study, including studies of natural history, serologic evaluations, and treatment protocols. Consent, if only informal, is also sought when a child approaches death and treatment is withdrawn or withheld. Who should provide consent for these children in lieu of their natural parents?

Individual states, communities, hospitals, and practitioners have developed strategies for handling this problem, but a uniform approach is required. Some states have given full power and responsibility to local child protective agencies. Others have identified the judiciary as the source of consent. Some states agree to involve foster parents in decisions concerning the child's care; others exclude their input. Unfortunately, erratic, bureaucratic policies have resulted in the exclusion of these children from treatment and diagnostic studies as well as in delays in the management of their acute and chronic medical problems. A consensus must be reached on our approach to this issue. The development of a national policy group to examine the intricacies of this problem and forward policy recommendations is long overdue.
Children without natural parents deserve the same care and treatment as those who have them. New medications and diagnostic procedures may only be available experimentally and, therefore, require consent for their use. The exclusion of these children from using these modalities may impede their care. Also, vital information about the disease and drug efficacy can only be obtained if adequate numbers of children are enrolled in clinical studies. All infected children will benefit from these studies and the option for enrollment must be made readily available.

Finally, who will be at the bedside of the dying child? Decisions to discontinue treatment or to allow a child to die in comfort are traditionally made with the family. These are not decisions that require consent only; they also require the advice of a devoted caretaker. Who will provide this guidance for children without parents? Until these issues are formally addressed many of these decisions will remain entirely in the realm of the health care providers.

IMPLICATIONS OF A CHRONIC DISEASE

Human immunodeficiency virus is still primarily a disease of infants and young children. However, 30% of the reported cases of AIDS are diagnosed in children 2 years of age or older. The introduction of azidothymidine (AZT) and other antiviral agents, as well as improved general medical treatment, can lead to an increased lifespan for many infected children. The approach to HIV has moved further from the concept of a fatal infection to one of a chronic disease of childhood. Not unlike infected adults, many children are learning to live with the limitations set by their disease.

Families and caretakers of infected children should be counseled about the nature of the infection. Children will require ongoing, lifelong treatment. As the trend in antiviral treatment approaches the pattern of chemotherapy for cancer, we can expect long-term, multiple drug regimens combining oral and intravenous treatments. The natural history of the disease includes frequent exacerbations involving multiple organ systems. The concept of long-term, complex medical therapy should be presented to caretakers and reinforced over time.

Treatment and care must be modified to accommodate the developmental and social needs of the older child. Older children need to be informed about and involved in their care. At times, this involves simply allowing the child to choose which hand he prefers for the intravenous line and, at other times, it entails allowing the child to refuse therapy. The child must be considered an important participant in decisions about care. The psychological needs of older children are extremely important. The child's fantasies about the disease and treatment may impede care and cause undue fear and anxiety. Open and intimate discussion with the child proves helpful in allaying these anxieties. Preparation for procedures and new treatments is necessary as well.

Older children who are critically ill or dying may set limits about what they are willing or able to discuss. However, an open and honest relationship must be available. Like all other dying children, the fantasies of HIV-infected children may be more fearsome than the reality, and the opportunity to share them may, in itself, be therapeutic.

The development of treatment protocols and drug regimens should take into consideration the needs of the school-aged child. All attempts need to be made to keep children in school when they are well. This may include the need to limit medical interactions or to develop late afternoon and evening clinic sessions. Medication schedules also may require adjustment to accommodate the child's daytime schedule. Other children may require tailored educational settings to meet HIV-related developmental and neurologic disabilities.

Finally, for older children, their level of awareness about their disease as well as their environment requires careful attention. These children, while suffering the medical manifestations of the infection, often watch the illness affect their parents and siblings; many children have lost parents or siblings to AIDS by the time they reach school age. Psychologists, previously involved in the documentation of the effects of the disease, may be called on to provide supportive and therapeutic work. Ongoing supportive therapy will be necessary to help these children work through family losses as well as concerns about their own morbidity and mortality.

HIV is also a chronic infection in the adult population. The need for early medical intervention and ongoing treatment is crucial for the maintenance of good health. However, monthly appointments for the child and the adult may appear prohibitive and time consuming for them. A family approach to care with the integration of medical and social services for the mother and child will enhance compliance and treatment. This need requires the establishment of clinics and treatment facilities where women and their children can be seen simultaneously. The long-term provision of family-oriented social and psychological services will also be fostered in this setting.

PEDIATRIC HIV INFECTION: AN INNER CITY DISEASE

Pediatric HIV disease is increasingly becoming a disease of black and Hispanic children of the inner cities. Born to women involved in the drug culture, these children often begin life facing multiple complex social and economic issues. HIV disease can be added to a long list of social ills including poverty, drug use, limited economic and educational opportu-
nities, and a general sense of hopelessness.

In our experience, successful management of the HIV-infected child must include a willingness on the part of the health care team to acknowledge and address the full battery of social issues. This may include helping families to navigate the social service bureaucracy or to provide emergency diaper and infant formula when these cannot be provided otherwise. Parents may be unable to focus on the complexities and responsibilities of sophisticated medical treatment if distracted by the daily need to provide food, clothing, and shelter for their children.

Economic resources for health and social services for the indigent have been severely curtailed during the last decade. Children with HIV infection are often cared for at underfunded municipal hospitals supported by local governments. Resources for their care and treatment may be limited by the financial and bureaucratic constraints common to inner city hospitals. In addition, funding for research and experimental treatments are concentrated at tertiary care centers, further limiting access to treatment. However, funding agencies are slowly beginning to acknowledge the need grant research awards that utilize new treatment protocols at inner city health centers. This may result in the adjustment of traditional research expectations to accommodate the limited resources of inner city health centers, as well as additional funding to augment care services.

At our institution, as in any centers caring for inner city children, pediatric HIV research and direct medical care have been integrated. In a population already overwhelmed by social disorganization and an endless stream of bureaucracy, the decision to integrate care and research has been critical. Funding agencies have begun to recognize the need to provide adequate resources in order to accomplish successful scientific research.

Finally, children with HIV infection are an unheard, unrepresented constituency. They have few advocates. Women and children in poverty have always been a powerless, voiceless minority in our society. The rise of HIV infection has led to further alienation and disenfranchisement. The social stigma of the disease and its associated morbidity and mortality have created a pervasive silence within our society.

The rising number of at-risk and HIV-infected children will continue to provide challenges to their health care providers. Attention to the medical and scientific issues of the disease must go hand and hand with psychological and social concerns for the family. The recognition of pediatric HIV infection as a potentially chronic disease of inner city children and their families will facilitate planning of appropriate programs and services. This approach should prove invaluable for both the provision of quality care, as well as the attainment of research goals.

SELECTED READINGS


