

Children and Adolescents Living with HIV and AIDS: A Review

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Worldwide, more than one million children are infected with human immunodeficiency virus (HIV) and in the United States it has become the sixth leading cause of death among 15–24-year-olds. Despite the trend of increasing rates of infection, advances in therapies have led to survival past 5 years of age for more than 65% of infected children. This global health threat will therefore continue to have a significant impact on child and adolescent psychiatry and psychology. This paper reviews current studies and reports on the consequences of the acquired immunodeficiency syndrome (AIDS) epidemic in the psychiatric care and development of children and adolescents infected by HIV. From a search of all the English-language-based literature on pediatric AIDS, 140 studies are reviewed which address HIV infection and its psychological and social implications. Several topics of mental health significance are examined: (1) the epidemiology of HIV, (2) neurocognitive development among those infected, (3) psychological impact of infection, and (4) the family and social context of HIV. The transition of HIV from an acute, lethal disease to a subacute, chronic disease has enormous implications for the neurocognitive and psychosocial development of children and families. As children and adolescents infected with HIV continue to live longer, normal developmental milestones and educational needs will take on new significance. Many children will continue to be adversely impacted by non-HIV factors such as poverty, inadequate medical services, and a lack of social support. This review outlines recent developments that hold promise to effectively reduce the treatment burden on the infected, their families, and health care providers and to decrease the incidence of transmission to the uninfected.

Keywords: Pediatric, HIV, AIDS, consultation-liaison.

Abbreviations: AIDS: acquired immunodeficiency syndrome; CNS: central nervous system; CT: computed tomography; DDI: Dideoxyinosine; HAART: highly active antiretroviral therapy; HIV: human immunodeficiency virus; PCR: protein chain reaction; PE: progressive encephalopathy; SSRIs: selective serotonin reuptake inhibitors; STD: sexually transmitted disease; ZDV: zidovudine.

Introduction

Human immunodeficiency virus (HIV) is a global health threat of significance to child and adolescent psychology and psychiatry. The rapidly expanding literature on pediatric acquired immunodeficiency syndrome (AIDS) and HIV documents the consequences of the epidemic in the care and development of youth infected by HIV and in the change of risk behavior among both the infected and the uninfected. HIV is the prototypical biopsychosocial disease and there is important research at every organizational level from the cellular to the societal. This review will focus on several clinical, diagnostic, and treatment topics of greatest significance for child and adolescent psychiatry and psychology: (1) the epidemiology of HIV, (2) neurocognitive develop-

ment among those infected, (3) psychological impact of infection, and (4) the family and social context of HIV. In each of these areas, contextual factors are crucial. For people living with HIV, medical and social issues are highly interrelated. The social context for many children and adolescents with HIV involves poverty, a lack of resources, and multiple family losses. These factors may impact adherence to medications, delivery and utilization of treatment services, family relationships, bereavement, and disclosure of illness. Cultural beliefs also influence how people cope with illness and loss. Cultural attitudes may determine an individual's behavior and reactions to disability or death, the role of families in medical treatment, and the nature of community support for an illness. Each of these factors are particularly relevant to pediatric patients. As suggested in the next section, the current epidemiology of HIV indicates that the infection will continue to involve child and adolescent psychology and psychiatry in future decades. Fortunately, recent developments hold promise to effectively reduce the treatment burden on the infected and to decrease the incidence of transmission to the uninfected.

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The Changing Epidemiology of Child and Adolescent HIV

Of the more than 7 million cases of AIDS reported worldwide, more than 1 million are children (UNAIDS, 1998). Even a decade ago, in a representative survey in the United States, 61% of child and adolescent psychiatrists had already treated an HIV-positive child and the vast majority were concerned about the influence of HIV upon their practices (Brown, Etemad, Brenman, & Dwight, 1991). All indications are that this trend will continue. In the U.S., one quarter of all new HIV infections occur among those under the age of 22 and over half occur among those under the age of 26 (Office of National AIDS Policy, 1996). There are more than 2000 children under the age of 13 with AIDS in the United States, and AIDS is now the sixth leading cause of death in 15–24-year-olds. HIV infection rates are increasing most rapidly among heterosexual women and young people in racial and ethnic minorities (National Institutes of Health, 1997). Pediatric AIDS, similarly, is found disproportionately among families of color. Demographic data gathered in the AIDS Costs and Service Utilization Survey found that 62% of pediatric AIDS patients were African American, 25% Hispanic, and 10% White (Fahs et al., 1994). HIV prevalence in women aged 20 and 25 years rose by 36% and 45%, respectively, mainly due to heterosexual transmission (Rosenberg & Biggar, 1998). For children and adolescents, there are no natural seroprevalence data. However, statistical procedures based on national AIDS case surveillance data and estimates of the time from HIV infection to AIDS diagnosis indicate that there are at least three HIV-positive young people for every known case of AIDS (Karon et al., 1996).

Internationally, HIV transmission is spreading more rapidly among women and young people than among other groups. In one study from 12 European countries, AIDS incidence data suggested that HIV transmission is decreasing among homosexual men and adult intravenous drug users, but increasing among young heterosexuals (Houweling et al., 1998). In underdeveloped areas of the world, such as eastern Africa, an increase in both adult and child mortality due to AIDS have led to a dramatic decline in life expectancy. In a rural area in Uganda, with an HIV prevalence of 8%, life expectancy has dropped from nearly 60 years to 42.5 years (Boerma, Nunn, & Whitworth, 1998). Child mortality rates by 2010 are expected to increase fourfold in Zimbabwe, threefold in Botswana, and to double in Kenya and Zambia due to AIDS (Foster, 1998). Women of childbearing age account for a substantial proportion of the individuals infected with AIDS in Africa. The prevalence of HIV in the Ivory Coast is at least 10% in each region, with women aged 20 to 29 the most likely to be infected (Sangare, Coulibaly, & Ehouman, 1998). These trends are evident outside of Africa as well. For example, prevalence of HIV in pregnant women has increased steadily in Bangkok from 1991 (1.1%) to 1996 (2.3%) (Siriwasin et al., 1998). In Puerto Rico, the proportion of AIDS cases that are women has increased dramatically (from 45% in 1993 to 64% in 1995) because of heterosexual contact, representing the fastest-growing category of AIDS cases on the island (Perez-Perdomo, Suarez-Perez, & Perez-Cardona, 1997).

Despite international trends of increasing infection, advances in therapies have led to more than 65% of

children with HIV living past 5 years of age. Many of these children will become involved with mental health professionals (Bachanas, Kullgren, Morris, & Jones, 1998). Even without medical treatment, a small number of HIV-infected children may remain asymptomatic for as long as a decade. Thus the medical causes and psychological consequences of prolonged nonprogression continue to be an important area of research (Ammann, 1994).

Routes of Transmission

Routes of transmission of HIV are well known and understood. Among adolescents, sexual intercourse continues to account for the majority of new AIDS cases. The preponderance of sexual risk for young males is through same-sex contact and for young females is heterosexual contact (Centers for Disease Control and Prevention, 1997). A small percentage of cases may be attributed to sexual abuse (Stolar & Fernandez, 1997). Pediatric AIDS is predominantly a result of maternal transmission. The epidemiology of HIV in childhood is essentially the epidemiology of HIV infection among childbearing women (Pavlakakis et al., 1994). Forty-five per cent of children with AIDS have mothers who used intravenous drugs and another 20% were born to women whose partners were intravenous drug users (Havens, Whitaker, Feldman, & Ehrhardt, 1994).

Approximately one quarter of infants born to an untreated HIV-infected mother will also be infected (The European Collaborative Study, 1994). Several projects around the world have demonstrated the efficacy of zidovudine (ZDV) for reducing maternal transmission to as little as 8% (Alonso Arias et al., 1998; Connor et al., 1994; Lewis, Haiken, & Hoyt, 1994; Rowe, 1997; Rutter, 1998; Wongchoosri et al., 1998). Pre- and perinatal administration of ZDV has been shown to reduce vertical transmission of HIV by over half (Wade et al., 1998). In a study of deliveries by HIV-positive women in London, Gibb et al. (1997) conclude that the number of vertically infected babies born in London could be reduced by two thirds if all HIV-infected women in London consented to testing and intervention. In addition to the obvious implications of reduction of HIV infection, these studies have given rise to urgent appeals for mandatory testing of pregnant women. The majority of hospital-based pediatricians in New York City who responded to a survey agreed that all women seen for prenatal care in a metropolitan health center should be screened for HIV and that high-risk newborns should be screened regardless of parental consent (Bhushan & Cushman, 1995). However, the benefits of mandatory HIV testing compared to risks from an anticipated decrease in prenatal care to avoid testing before delivery have not been substantiated (Nakchbandi et al., 1998).

HIV can also be vertically transmitted in breast milk (Stolar & Fernandez, 1997; Tess, Rodrigues, Newell, Dunn, & Lago, 1998). Multiple factors influence the role of breast milk in maternal transmission of HIV. Recent prospective studies have found an increased risk of transmission in the early months of breastfeeding compared to the later stages (Dunn, Tess, Rodrigues, & Ades, 1998; Miotti et al., 1999). In developing countries, there is bitter debate over the benefit of nutritional programs supplying formula in order to discourage breastfeeding by known HIV-positive women or in areas with extremely high prevalence rates (Gibb et al., 1997; Latham &

Greiner, 1998; D. L. Woods, 1998). Other factors not related to breastfeeding that influence transmission include the extent of exposure to HIV *in utero* and intrapartum. A study on the risk of vertical transmission of HIV in 553 children born to HIV-infected women found that some of the factors associated with transmission were the severity of maternal HIV, amniocentesis, breastfeeding, and specific blood types (which may be a marker for genetic susceptibility to infection) (Tess et al., 1998). The available research indicates that there is some transmission of HIV due to breastfeeding, but many factors influence transmission risk, including the age of the child, severity of maternal HIV, and vitamin deficiency. For example, among non-breastfeeding women ($N = 133$), Greenberg et al. (1997) found that increased risk of maternal-infant transmission was associated with severe vitamin A deficiency. Specific recommendations are difficult to propose due to the numerous cultural, political, and geographical controversies in resource-poor settings (Bobat, Moodley, Coutsooudis, & Coovadia, 1997; Fowler, Bertolli, & Nieburg, 1999).

Testing and Diagnosis

Rapid tests provide results within the same day rather than requiring a 2–3-week waiting period. This quick response reduces the negative psychological consequences associated with a long wait and the significant “no-show” rate for test results. To evaluate the use of rapid testing with same-day results in public clinics, the Single Use Diagnostic HIV-1 rapid assay was used for a 3-month period at an anonymous sexually transmitted diseases (STD) clinic in Dallas, Texas (Kassler, Dillon, Haley, Jones, & Goldman, 1997). Rapid on-site testing was feasible, no more costly than standard testing, and preferred by clients. When it was used, more persons learned their serostatus, and counseling and testing were just as effective. Similarly, a study by Wilkinson et al. (1997) found that rapid testing, even in a high-prevalence, resource-poor rural hospital, was feasible, accurate, highly cost-effective, and substantially increased the number of patients who received post-test counseling. In Lusaka, Zambia, clients of a 1-day voluntary testing and counseling program reported high levels of satisfaction with the services and 92% preferred to receive results and counseling the same day (McKenna et al., 1997).

The diagnosis of HIV is also changing rapidly. Protein chain reaction (PCR) techniques allow accurate and cost-effective detection of HIV antigens, rather than antibodies (Stetler et al., 1997). PCR tests also detect exposure to more than one HIV virus and may contribute to a more accurate monitoring of the prevalence of dual infections (Ishikawa et al., 1998).

Neurocognitive Development

One of the challenges of understanding HIV in children and adolescents is determining which of the biological, psychological, neuropsychiatric, and social factors is most relevant at any given moment. Many infected children may have no medical symptoms and their developmental progress may be more influenced by poverty and a lack of resources. For those that present with behavioral and developmental symptoms, the specific etiology of these symptoms is often unclear. In seropositive children, subtle neuropsychological deficits

may be due to the central nervous system (CNS) effects of HIV infection, prenatal insults, other diseases (such as infections, strokes, or neoplasms) or environmental circumstances (Armstrong, Seidel & Swales, 1993). In fact, health status and wellbeing in HIV-infected children may be significantly related to medical and social factors not directly associated with the virus. Adolescents with HIV infection are more likely to report limitations that are behavioral and emotional rather than physical, which suggests the complexity of their impairment (Remafedi, 1998).

This section will review recent development on neurocognitive aspects of HIV infection among children and adolescents. HIV-associated progressive encephalopathy (PE) is characterized by a triad of symptoms including impaired brain growth, progressive motor dysfunction, and loss or plateauing of developmental milestones (Mintz et al., 1996). Among HIV-infected children, PE has an estimated prevalence of 13 to 23% (Lobato, Caldwell, Ng, & Oxtoby, 1995). The course of PE in infants and young children may be related to the time of infection in brain development, the particular strain of HIV, or genetic vulnerabilities. Some subgroups of young people, such as those with hemophilia, have a lower incidence of HIV-associated neurologic disease. Only longitudinal assessments allow HIV encephalopathy to be distinguished from mental retardation secondary to other causes, such as maternal drug addiction and inadequate prenatal care (Centers for Disease Control, 1996). Despite the general fact that PE is observed only when immunosuppression is present, in children there is no obvious correlation between encephalopathy and immunologic status (Pavlikis et al., 1994). That is, current markers of immunologic functioning (e.g. CD-4 count) do not correlate with degree of impairment.

Although many children with HIV are asymptomatic, numerous studies document the occurrence of at least some cognitive and language delays as a result of HIV; these may be quite subtle. The mechanism of brain impairment due to HIV is not completely understood. Findings from autopsy studies of patients with PE include decreased brain weight, inflammatory changes, calcifications of basal ganglia vessels, white matter degeneration, and astrocytosis (Stolar & Fernandez, 1997). Proposed mechanisms for the pathogenesis of HIV-mediated CNS disease include direct neuronal injury, macrophage destruction that results in neurotoxicity, dysfunction caused by viral products, neuroreceptor blockade, coinfection by other agents, autoimmunity, antibody-mediated cellular toxicity; integration of the provirus in CNS cell lines; and alteration of the blood-brain barrier (Belman, 1992; Stolar & Fernandez, 1997). Three patterns of abnormal neurocognitive development have been described: (1) rapid PE with loss of attained milestones, (2) subacute progression of encephalopathy with relatively stable periods, and (3) static encephalopathy with a failure to achieve new milestones (Belman, 1992). Regular neurologic and psychometric testing is recommended to further differentiate these patterns. In a sample of 87 previously untreated children with symptomatic HIV, Brouwers et al. (1995) found the overall computed tomography (CT) brain scan severity rating was highly predictive of the level of cognitive functioning. There was a higher rate of CT abnormalities (cortical atrophy, ventricular enlargement, white matter changes) in vertically infected children as compared to transfusion-infected children. Intracerebral calcifications

were only seen in the vertically infected group. In a study of 40 children with symptomatic HIV infection, high levels of the neurotoxin quinolinic acid in the cerebrospinal fluid have been correlated with encephalopathy, decreased performance on IQ tests, increased mortality, and inflammatory neurologic disorders (Brouwers et al., 1993).

Retrospective data on 90 school-age children with HIV were collected by Papola, Alvarez, and Cohen (1994) in order to describe their developmental functioning and service needs. They found that 44% of the 86 HIV-infected children were functioning in the below-average to average range of intelligence, and 56% demonstrated significant language impairments. A recent study conducted by Bachanas et al. (1998) reports that WISC-III scores and academic achievement scores of older HIV-infected children were significantly below average, with associated impairments in psychological functioning. Some research also indicates that expressive language is significantly more impaired than receptive language in HIV-positive children. In a sample of 36 HIV-infected children under the age of 10 years, CT scan abnormalities were significantly correlated with poorer receptive and expressive language functioning, and expressive language was more severely impaired than receptive language among those children with encephalopathy (Wolters, Brouwers, Moss, & Pizzo, 1995). Visual-motor skills are also frequently impaired. A study of 27 HIV-positive children aged 6 through 17 found that status of visual-motor skills was the cognitive domain most related to stage of disease, mode of transmission, and the children's living environment (Frank, Foley, & Kuchuk, 1997).

It is also difficult to distinguish the impact of environmental variables on cognitive functioning in HIV-positive children. For example, in the recent study by Bachanas et al. (1998), language deficits were associated with poverty in the household, and math deficits were associated with the presence of an AIDS diagnosis, although the causal nature of these relationships could not be determined. Although earlier studies implicated nutritional status as a mediator of cognitive status because of the weight loss associated with late stage disease, recent research has not substantiated the relationship. The correlation between weight gain and decrease in ventricular brain ratio suggests that malnutrition could be a factor, but CNS-specific factors and antiretroviral pharmacokinetics have been found to correlate more closely with cognitive improvement (Brouwers et al., 1996).

Antiretroviral Therapies and Neurocognitive Functioning

Antiretroviral drugs inhibit or halt the progression of HIV and thus improve most indices of general health in pediatric AIDS. In addition, there is evidence that these drugs improve cognitive deficits in children with AIDS, at least for a limited period of time. The report by Pizzo et al. (1988) was the first study to demonstrate that ZDV given by continuous IV for 6 months improved cognitive status in symptomatic children. Follow-up data on 13 of 21 children (mean age 4.8) revealed a mean increase of 1 standard deviation in a General Index of Mental Abilities. Neurocognitive improvement occurred for children receiving treatment regardless of the presence of encephalopathy at baseline and was independent of immune status.

Subsequent studies have been more inconsistent but have yielded similar findings (Stolar & Fernandez, 1997; Wolters, Brouwers, Moss, & Pizzo, 1994). The most contradictory result was a 1-year intervention with 54 relatively healthy children (mean age 3 years), which found no change in cognitive functioning with ZDV treatment for 12 months (Nozyce et al., 1994). Despite treatment, immune status as reflected by CD-4 count deteriorated for many subjects, suggesting disease progression. Brady et al. (1996), in the largest study to date, with children aged 3 months to 12 years, found an improvement in cognitive abilities over a 36-month protocol, with improvement most marked for patients 6 years or older. In addition to treatment resulting in improved cognitive status, several studies of small samples have demonstrated improved adaptive functioning with antiretroviral treatment (Brivio, Tornaghi, Musetti, Marchisio, & Principi, 1991; Brouwers et al., 1994; Moss et al., 1994). A treatment study with 25 children aged 1 to 12 (mean age of 5.3 years) found that half of the group was encephalopathic at baseline (Wolters et al., 1994). Treatment resulted in a significant improvement in communication, socialization, and daily living, as measured by the Vineland Scales. Motor skills, however, did not improve.

Antiretroviral agents other than ZDV are now commonly used, and the results in adults with AIDS are promising (Pediatric AIDS Foundation, 1994). However, other than one case study (Tepper et al., 1998), only one of the projects that are underway to assess cognitive effects in children has been published (Butler et al., 1991). This project found, in a sample of 43 children aged 3 months to 18 years, that the drug Dideoxyinosine (DDI), given in 3 divided doses for a minimum of 24 weeks, was well tolerated and showed some promise in both previously untreated children and in those who had been refractory or intolerant of previous antiretroviral therapy. Cognitive status was determined by a battery of age-appropriate assessments such as the Wechsler Intelligence Scale for Children-Revised (6 to 16 years), the McCarthy Scales of Children's Abilities (30 months to 6 years), and the Bayley Scales of Infant Development (2 months to 30 months). Cognitive improvement was detected in a quarter of those with an IQ score less than 100 at baseline and was correlated ($r = .39$) with plasma concentration of DDI. These results are suggestive that appropriate antiretroviral treatment can reverse, at least temporarily, HIV-related cognitive deficits.

Establishing the efficacy of antiretroviral treatment for neuropathology in pediatric AIDS patients is difficult because of our limited understanding of the factors that mediate change in neuropathology and cognition. There is evidence that greater efficacy of treatment is associated with greater brain impairment before treatment and better CNS penetration of the antiretroviral agent (Brouwers et al., 1994). Other factors that moderate treatment are less clear. For example, in a study of 8 children aged 2 to 14 years who were treated for 6 months with continual infusion of ZDV, significant decreases in ventricular area and ventricular brain ratio were seen on MRI. Improvements were seen in IQ scores taken simultaneously but did not correlate significantly to the amount of decrease in the ventricular areas (DeCarli et al., 1991).

Despite the generally positive results from ZDV treatment in virologic parameters, cognitive status and adaptive functioning, the effect is not sustained in many

Table 1
Antiretroviral Medications Available for HIV

NRTI agents	NNRTI agents	PI agents
Zidovudine	Nevirapine	Indinavir
Didanosine	Delavirdine	Nelfinavir
Lamivudine	Efavirenz	Ritonavir
Stavudine		Saquinavir
Zalcitabine		Amprenavir
Abacavir		

NRTI: nucleoside analogue reverse transcriptase inhibitor; NNRTI: non-nucleoside analogue reverse transcriptase inhibitor; PI: protease inhibitor.

children beyond 6 months of treatment (Tudor-Williams et al., 1992). This short-term effect underscores unanswered questions concerning the mechanisms of change resulting from antiretroviral treatment, the influence of general medical management, the development of viral resistance, the role of multi-drug therapy, the use of alternative therapies, and the search for a "gold standard" of treatment. These questions are difficult to answer since the research is inherently limited by naturalistic research conditions and small samples. For example, because of the urgency for therapy, antiretroviral treatment cannot be delayed using standard, wait-list control groups. Furthermore, patients enrolled in clinical trials have often received varying degrees of prior treatment, have different levels of resistance to pharmaceutical agents, and present with symptoms characteristic of different stages of AIDS, thus confounding treatment comparisons. Yet, despite the lack of consensus and the methodological barriers to case-controlled research, there appear to be clinical benefits of antiretroviral therapies for treatment of neurocognitive dysfunction in children and adolescents with AIDS.

Drug interactions. There are three main categories of antiretroviral medications, each with numerous side effects and special instructions on administration (Centers for Disease Control and Prevention, 1998). Since these medications are relatively new, behavioral and cognitive side effects are rarely mentioned. Moreover, the pharmacokinetics of these drugs and the impact of these medications on the developing nervous system is unknown. The three classes are shown in Table 1. In general, the fragility of the HIV-infected patient's nervous system must be considered when administering psychotropic medications. Non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs) are inhibitors of the cytochrome P enzyme. Since this enzyme is responsible for the metabolism of many commonly prescribed drugs, it creates the potential for drug interactions (Deeks, Smith, Holodny, & Kahn, 1997). In general, these medications are not recommended for concurrent use with antihistamines and sedatives-hypnotics, or amphetamines. The protease inhibitor agents inhibit enzymes responsible for the metabolism of antidepressants such as bupropion hydrochloride and anticonvulsants such as carbamazepine. Drug interactions are particularly difficult to determine in complex protocols, such as the use of multiple drug therapies in combination with a protease inhibitor, known as highly active antiretroviral therapy (HAART). In addition, there is a wide range of drugs used in the prevention of opportunistic infections, many of which have an effect on the CNS and have the potential for drug-drug interactions (Centers for Disease Control and Prevention,

1998; Enting et al., 1998). Also, HIV-infected patients are noted to respond to lower levels of psychotropic medications than do their noninfected peers. Drugs like amitriptyline, trimipramine, and imipramine should not be used in patients with cognitive impairments or dementia due to the risk of central muscarinic effects (Fernandez & Levy, 1994).

The complicated relationship of HAART to psychotropic medications due to shared degradative metabolic pathways is just beginning to be elucidated and the clinical efficacy of multiple regimens is virtually uncharted territory in children and adolescents (Gonzalez & Everall, 1998). A recent study found that individuals treated with interleukin-2 (IL-2) and HAART showed significantly fewer resting CD4+ T cells harboring HIV in the bloodstream than those patients receiving HAART alone (Chun, 1999). Such therapies may reduce at least one of the "reservoirs" of HIV. It is a challenge for mental health providers to incorporate and respond to the changes in the treatment of HIV.

Adherence. Most antiretroviral regimens are complex and challenging. Rigorous adherence to them is important because a decrease in drug levels due to inconsistent doses may cause viral resistance. It is hoped that better adherence will result in decreased viral loads and improved immune status. Mental health providers can be especially helpful in assessing and maintaining adherence. A thorough evaluation is needed of caregivers and their environments, the ability and willingness of a child to take medications, and the status of disclosure (Shave & Nelson, 1998). The lack of disclosure of infection, for example, may lead to relabeling or hiding of medications, perhaps not wanting to fill them at local pharmacies, or missing doses when the child is not home. Social stigma and fear of disclosure may, in fact, be more influential than other co-occurring factors, such as socioeconomic status and high-risk lifestyles. In a group of high-risk young people attending a multidisciplinary clinic for HIV-infected adolescents, researchers found that an adolescent's level of high-risk behavior did not predict nonadherence (Belzer, Fuchs, Tucker, & Slonimsky, 1998). Currently there is no evidence to support denial of antiretrovirals to children and adolescents from "high-risk" backgrounds based on the supposition that they are at greater risk for nonadherence.

AIDS clinical treatment trials now acknowledge that adherence to regimens and protocols is of central importance. For this reason, many trials occur in family-centered, multi-disciplinary settings to facilitate adherence. One multi-site study found that trial treatment participation was associated with better clinic attendance and less use of emergency services (Fahs et al., 1994). Preliminary data from a project for HIV-infected adolescents in HAART educational groups suggests that infected youth will develop and share specific strategies for taking their medications and learn stress management techniques for coping with HIV in a supportive peer context (Lyon et al., 1998).

Psychology of HIV

In adults and children, coping with HIV infection is a complex phenomenon involving multiple interacting variables. Pediatric HIV patients experience more subjective distress than their uninfected peers as a result of the deterioration of developmental skills and the many stressors associated with HIV infection (Trad, Kentros,

Solomon, & Greenblatt, 1994). Such stressors often include the disclosure of HIV infection, social ostracism, fears of death, and family conflict. In addition, there are often instrumental problems in obtaining adequate health care services, medication, transportation, clothing, counseling, recreation, and housing (Hansell et al., 1998). Repeated hospitalizations and isolation from peers are known to have an adverse effect on the HIV-infected child's social, cognitive, and communicative development (Task Force on Pediatric AIDS: American Psychological Association, 1989). Psychological dysfunction is also associated with poor social support and school performance. Each identification and intervention with distressed children and early intervention may improve the child's quality of life. This section will review psychiatric disorders and coping styles associated with infection as well as the familial-social context of HIV. As described below, children and adolescents with HIV experience more subjective distress than their uninfected peers, including dysphoria, hopelessness, preoccupation with their illness, and poor body image. Some adolescents with HIV report more sexual risk-taking behavior and conduct or hyperactivity disorders. Many individuals with HIV have a history of negative life events, such as forced disclosure, loss of a parent or sibling due to AIDS, or abuse.

The cultural context of HIV transmission is an important factor in the care of infected youth (Williams & Ponton, 1992). Cross-cultural studies of the psychological processes triggered by HIV infection suggest that people of different backgrounds cope with HIV and AIDS according to their own social mores and cultural traditions. As illustrated in a comparative analysis of health care providers in the United States, Canada, India, and Thailand (Brachman et al., 1996), health professionals in some locales have a limited knowledge of HIV diagnostic issues and have little experience working with patients with HIV and AIDS. The cultural context of those infected (as well as of the providers) must be addressed in order to improve both prevention and treatment efforts. In India, for example, HIV infection has been associated with extreme reactions of shame, fear, humiliation, and anger (Ponton & Lees, 1998). Health providers in India have increased public awareness of the cultural basis of these emotions and thus somewhat decreased the negative impact of HIV on the lives of those infected. Similarly, because of greater social acceptance of HIV infection among young people, combined with advances in drug therapies, HIV diagnosis in the United States today does not have as profound a negative impact as it once had.

Psychiatric Symptoms and Interventions

Despite the decline in overt stigma towards the HIV infected, and promising medical advances, individuals with HIV continue to experience psychological distress. There have been concerns about increased depression and suicidality among HIV-positive adults. Lifetime rates of a depressive disorder in HIV-positive adults range from 32–56% (Ferrando, Goldman, & Charness, 1997). In addition, suicidal ideation has been associated with HIV infection in homosexual and bisexual men in Australia (Kelly et al., 1998). However, little is known about mood disorders, suicidality, and prior psychiatric history among HIV-positive children and adolescents. In fact, many of the studies report symptomatology rather than diagnoses or combine these data. In one study of 34

HIV-positive adolescents, 44% presented with current major depression, 85% had at least 1 Axis I DSM-IV diagnosis determined by structured clinical interview (SCID-P), and 53% had a history of psychiatric diagnosis prior to diagnosis of HIV infection (Pao et al., in press). Diagnosis of a mood disorder can also be complicated by neurophysiological factors. For example, a child with AIDS who is withdrawing because of physical pain may be incorrectly diagnosed as depressed (Stuber, 1992).

Several studies suggest that pediatric HIV patients, like adults, experience more subjective distress than their uninfected peers. In addition to symptoms of anxiety and depression, some parents also report more conduct or hyperactivity problems in their HIV-infected school-age children (Bose, Moss, Brouwers, Pizzo, & Lorion, 1994). Using the Child Behavior Checklist, Havens et al. (1994) found that a group of 26 HIV-infected children with prenatal drug exposure and a mean age of 7.1 years scored significantly higher on the internalizing, somatic complaints and depression/anxiety scales than did unrelated, uninfected children with prenatal drug exposure. Controlling for variables that influence distress, such as age, race, and IQ, did not alter the association between infection and symptomatology. Another study comparing 37 children with asthma, 17 HIV-negative children with hemophilia, and 6 HIV-positive children with hemophilia found that anxiety disorders were more frequent in the HIV-infected group than in the other two groups, while both groups of children with hemophilia were found to have lower levels of intrafamilial stress as compared to the asthma group (Bussing & Burket, 1993). It is possible that the low levels of intrafamilial stress may be the result of the extensive support networks of the National Hemophilia Program, indicating the complex relationship between disease, social support, and medical care (Cohen, 1994).

In addition to increased distress, adolescents with HIV often experience greater physical pain, which is a frequent accompaniment to AIDS. Chest pain, headache, oral cavity pain, abdominal pain, and peripheral neuropathy are commonly reported (Holland, Jacobsen, & Breitbart, 1992). Almost 60% of children with HIV experience pain, which may negatively affect their quality of life and sleep patterns (Yaster & Schechter, 1996). As in other chronic illnesses, pain needs to be understood within a developmental context so that preventive and therapeutic intervention strategies can be developed to reduce children's distress.

In contrast to these findings of increased distress, another study among 36 middle-class families found that HIV-seropositive children, as compared with a group of seronegative peers, scored significantly higher on the Perceived Competence Scale for Children, a measure of global self-concept, and significantly lower on measures of depression and anxiety (Bose et al., 1994). However, these parents reported that HIV-infected children were significantly more anxious, less socially active, and less academically successful than were their noninfected peers. The disparity between child and parent report of adjustment may have been due to the lack of HIV-related symptoms in this sample, which allowed the children to deny the reality of the disease. In addition, the parental report may have reflected their own anxiety stemming from the negative life events associated with HIV and AIDS. For example, in a survey of 101 parents of HIV-infected children, levels of state and trait anxiety and depression were significantly greater than those found in

a sample of parents of general medical patients and among parents of children undergoing treatment for cancer (Wiener, Theut, Steinberg, Riekert, & Pizzo, 1994). Although these studies compared infected and noninfected children, the cross-sectional assessments of relatively asymptomatic patients limits the generalizability of the results.

Treatment. As with other chronic illnesses, organic and psychosocial factors are tightly interwoven in the patient's overall condition. For example, in symptomatic adult patients with AIDS, affective disorders may contribute to somatic complaints, thus resulting in treatment with selective serotonin reuptake inhibitors (SSRIs) (Ferrando et al., 1997). Some HIV-infected children and adolescents may experience psychiatric conditions such as affective disorders, attention-deficit hyperactivity disorder (ADHD), mania, and psychosis. These disorders can lead to distress, frequent somatic complaints, greater risk of suicide, and poor compliance with medical care. Whatever the etiology of these psychiatric disorders, patients may benefit from psychotropic medications and psychiatric management that can improve symptoms and their quality of life.

SSRIs such as fluoxetine have been shown to decrease affective and somatic symptoms of depression, with a response rate of 83% in a sample of 33 depressed HIV-positive, symptomatic men and women (Ferrando et al., 1997). In some cases, depressed adult patients with HIV infection respond equally well to tricyclic antidepressants, dextroamphetamine, or testosterone as compared with placebo controls (Wagner, Rabkin, & Rabkin, 1996). Such clinical data in adults underscore the need to tailor different pharmacologic and psychotherapeutic treatment approaches carefully. For example, in adults, cognitive-behavioral techniques are often used to treat situationally appropriate anxiety while benzodiazepines may be effective in relieving anxiety and insomnia resulting from HIV encephalopathy and the side effects of ZDV treatment (Fernandez & Levy, 1994).

Little data are available on the treatment of psychiatric disorders and somatic complaints in children and adolescents with HIV. It is likely that the types of useful treatments and effectiveness of medication are generally similar to the treatment approaches among noninfected patients. HIV-infected patients with behavioral changes first require a thorough neurological assessment and review of their antiretroviral treatment. HIV-infected patients tend to be more sensitive to side effects and require lower doses of psychotropic medications. Several case reports illustrate the range of medication alternatives for HIV-infected children for symptoms suggestive of ADHD, depressive disorders, or chronic pain. Cesena, Lee, Cebollero, and Steingard (1995), for example, described a single case report of a 4.8-year-old Hispanic male with an abrupt onset of ADHD that was unrelated to ZDV treatment. The boy was treated successfully for ADHD and insomnia with clonidine. Similarly, one 15-year-old boy with hemophilia presented with depression that was unresponsive to adequate doses of imipramine and lorazepam. Multiple medications for pain were unsuccessful but there was a "marked improvement" with methylphenidate, 35 mg daily. Pain is a frequent accompaniment to AIDS. After the obvious medical causes have been treated and psychiatric conditions addressed, pain management deserves prompt attention as a specific problem (Schechter, 1993). For example, Anand, Carmosino, and Glatt (1993) note a case of an 18-

month-old male with AIDS and marked irritability who, after an extensive and unrevealing medical work-up, responded well to morphine, which was then tapered over several days without pain recurrence.

Coping with Illness

Coping responses to HIV infection have been more extensively studied among adults than among children and adolescents. One study of 108 HIV-infected adults examined the relationship between coping styles and psychosocial variables (Grassi, Righi, Sighinolfi, Makoui, & Ghinelli, 1998). Forty three per cent of the sample reported symptoms of poor coping and maladjustment to HIV infection based on four subscales adapted for HIV from the Mental Adjustment to Cancer (MAC) scale: lower fighting spirit, higher hopelessness, anxious preoccupation, and fatalistic attitude. Poor coping was associated with psychological stress, repression of anger, external locus of control, and low social support. The data from this study support the hypothesis that coping with HIV infection is a complex phenomenon related to psychological stress, personality factors, and social support. Other studies in adults indicate that coping style is one of several variables that may influence the onset of emotional disturbances secondary to HIV infection (Fleishman & Fogel, 1994; Pakenham, Dadds, & Terry, 1994). The manner in which people cope with illness and loss is heavily culturally influenced. For example, Latino individuals, for whom death is a culturally accepted part of the life cycle, may not withdraw or deny the prospect of death as would a person of Anglo origin (Magana & Magana, 1992).

Children and adolescents living with HIV have to cope with multiple conflicts. Dysphoric feelings may stem from the physiologic effects of AIDS. They also have to cope with the emotional pain related to social stigma, isolation and hopelessness, forced disclosure, anxiety about their medical prognosis, loss and bereavement, and physical appearance and body image (affected by wasting and dermatologic conditions) (Lewis et al., 1994). Attempting to cope with HIV-positive serostatus may trigger social withdrawal, depression, loneliness, anger, confusion, fear, numbness, and guilt (Fanos & Wiener, 1994). Children, in particular, may feel that they did something terrible to deserve HIV and thus may develop severe feelings of guilt (Stuber, 1992). Noninfected siblings are also affected by HIV. Sibling relationships may be damaged by a fear of contagion or feelings of resentment towards the ill child. Because of these multiple difficulties, siblings of infected children also often experience problems in school (Fanos & Wiener, 1994).

The diverse stresses and contexts of HIV appear to give rise to multiple modes of adaptation and coping. For example, mothers of children with HIV infection have reported significantly more wishful thinking than mothers of either healthy children or children with cancer (Hardy, Armstrong, Routh, Albrecht, & Davis, 1994). In the absence of a proven cure for HIV, wishful thinking may be an appropriate coping mechanism for mothers of infected children. Self-criticism was also reported by more mothers of HIV-infected children than by those with children who have cancer. As might be expected, biological mothers expressed significantly more self-criticism than did foster mothers. Parental adaptation to HIV may be an important factor in determining the child's adjustment and response. In a meta-analysis of

38 studies investigating children's psychological and behavioral adjustment to various physical disorders, Lavigne and Faier-Routman (1993) found that parent and family risk factors were more strongly related to child adjustment than to specific disease and disability factors.

Some research illustrates how adaptation and coping styles are likely to have implications for individuals' quality of life and adherence to protective health behaviors. In a study to determine how 297 HIV-positive adolescents with hemophilia cope with reminders of their HIV status, Brown, Schultz, and Gragg (1995) found a significant degree of distress reported in response to HIV reminders even after years of knowing about their infection. A wide variety of coping strategies were used, with resignation, self-calming, and distraction most commonly reported, while self-blame, engaging in risky behaviors, thinking about sex, and drug and alcohol use were used least. Overall, distress about reminders of HIV appeared to be associated with ineffective coping strategies. These data suggest that any new reminders of infection, such as a change in treatment protocol, or the death of a friend or family member, could result in nonadaptive behaviors. Other research has found that HIV-positive adolescents with hemophilia may demonstrate significant use of denial as a coping mechanism, perhaps because they have used this strategy in the past to deal with their hemophilia (Olson, Huszti, & Chaffin, 1992). For example, levels of distress in HIV-positive boys with hemophilia were found to be lower than in their immediate family and less than other HIV-seropositive children.

Improving coping and adaptation. Interventions aimed at improving the coping style for HIV patients are needed (Grassi et al., 1998). By identifying HIV-seropositive children in distress and implementing early interventions to enhance coping, it is hoped that their quality of life will be improved (Havens et al., 1994). There are several reports of support groups for HIV-infected young people or structured programs that attempt to address these issues (Halperin, 1993; Klein, Forehand, Armistead, & Wierson, 1994; Mellins & Ehrhardt, 1994). One therapeutic strategy, borrowed from more extensive research on adult adaptation to chronic problems, emphasizes the use of "active" strategies, such as problem solving and help-seeking, rather than "passive" strategies, such as self-blame or resignation (Brown et al., 1995). Obviously, the utility of any strategy depends on the exact nature of the problem, resources available and individual abilities. Coping is also culture-dependent and influences the adaptiveness of each strategy. Some have suggested that "active" strategies are endorsed most by Western cultures and "passive" strategies may be more congruent in non-Western culture and tradition (Haghighatgou & Peterson, 1995; MacKenzie, Sloan, Hobfoll, & Jackson, 1998).

Safer sex and living with HIV. Although the literature on sexual risk-taking behavior in HIV-infected adolescents is limited, research concerning general HIV prevention programs provides useful ideas for risk reduction (National Institutes of Health, 1997). In general, personalized knowledge is a necessary but not sufficient condition for behavior change (Brown, Barone, Fritz, Cebellero, & Nassau, 1991). Safer sex interventions have attempted to enhance favorable attitudes toward condoms, build social skills, improve self-efficacy, and create supportive peer norms (Kalichman, Carey, & Johnson, 1996; Kim, Stanton, Li, Dickersin, & Galbraith, 1997;

Wren, Janz, Corovano, Zimmerman, & Washenko, 1997). Adolescent-specific factors, such as cognitive immaturity and exploratory learning behavior, need to be targeted by intervention programs, as well as a variety of other factors that moderate sexual behavior, such as impulsivity, distress, and adverse life experiences (Brooks-Gunn, Boyer, & Hein, 1988; Brown, DiClemente, & Reynolds, 1991; Emans, Brown, Davis, Felice, & Hein, 1991; Irwin & Millstein, 1997). Most programs targeting uninfected individuals attempt to increase perceived susceptibility to HIV and to increase desire for safety, although more appropriate goals for infected adolescents are to increase empathy and the desire for responsible behavior (Brown et al., 1998).

The few studies on sexual risk behaviors in adolescents living with HIV suggest that both psychotherapeutic and psychoeducational approaches are appropriate for interventions for infected youth. A psychotherapeutic approach addresses internal barriers, such as denial, to safer sexual behavior in HIV-positive adolescents (Henry, 1996). Particularly in the case of perinatally infected youth, HIV-positive adolescents may begin to consider sexuality by exploring their own and their parent's HIV infection, and to examine the conflicts associated with HIV that influence their perception of sexuality and relationships (Lewis et al., 1994). A psychoeducational approach is useful in reaching targeted, high-risk adolescent populations. A 12-month motivational skills-based intervention, comprised of two individual sessions, a peer group activity, and an extensive peer group retreat, was designed to improve safer sexual behaviors in a sample of 111 adolescents living with hemophilia and HIV (Brown et al., 1998). Condom use and non-penetrative safer sexual behaviors increased significantly over the intervention year, as did reports of self-efficacy for safer sexual behaviors. Moreover, participants who maintained or improved in safer sex behaviors were significantly more likely than their peers to have improvements in their perception of the support of peers for safer sex and for abstinence. These data suggest that effective approaches enhance motivation for responsible behavior by acknowledging anger concerning infection, improving skills in group settings, and reinforcing safer peer norms.

Familial-Social Context

The adjustment of children with HIV and AIDS is strongly related to contextual parent and family factors and often less related to disease and disability factors (Sherwen & Boland, 1994). Poverty, parent history of drug use, and multiple losses are among the family and social factors that influence many children and adolescents with HIV. The AIDS epidemic has left tens of thousands of children, many of whom are themselves infected with HIV, with dead or dying parents (Aronson, 1996). Throughout the world, in both underdeveloped and developed nations, poverty is a major barrier both to HIV prevention and treatment of those infected with HIV. In one study of 124 HIV-positive adults in Australia, for example, most participants reported severe financial pressure, and almost half were living below the poverty line (Ezzy, De Visser, Grubb, & McConachy, 1998). In the United States, inner-city families from minority backgrounds often lack social support and face multiple health threats. One study of minority, inner-city families found that infected parents felt more isolated and

reported fewer financial and support services than uninfected caregivers (Mellins & Ehrhardt, 1994).

In the United States, there is a high frequency of comorbid drug abuse and mental disorders in HIV-infected parents (Havens et al., 1994). Among children of parents living with AIDS, conflict between the parent and child has been found to be significantly associated with parental drug use. Children of intravenous drug users are at increased risk for prenatal drug exposure, neglect, abuse, foster care placement, and exposure to domestic violence (Goodman, 1998). Comorbidity in families presents numerous problems for child adjustment and family functioning, as well as treatment barriers. For example, physicians may be reluctant to prescribe narcotics for ill children for fear that the parents will abuse their children's drugs (Yaster & Schechter, 1996). At the same time, the influence of environmental co-factors must be understood in a cultural context. In a recent study of HIV infection in Latino and African-American families, the occurrence of stressful parenting events (e.g. arguments with their children) was associated with risky parental lifestyles (e.g. drug use and trading sex for money and drugs) (Rotheram-Borus, Robin, Reid, & Draimin, 1998). In White families, however, these stressful parenting events were not associated with the parent's risk-taking behaviors. These data suggest that ethnic differences may influence how families cope with an illness such as HIV and that the role of sociocultural beliefs must be further investigated.

Family-focused treatment. Some advocate a family-centered approach to treatment for HIV-positive children and adolescents (Mellins & Ehrhardt, 1994). Cohen (1994) suggests that pediatric HIV treatment should be understood in terms of three systems: (1) individual characteristics, (2) disease characteristics, and (3) family processes. Indeed, in certain culture groups, the family-centered approach is the most appropriate and often more effective than alternative models. In Latino culture, for example, the family is viewed as a vital aspect of treatment and education (Magana & Magana, 1992). According to this view, caretakers should take into account the positive and negative characteristics of the family structure and the influence of these patterns on the infected child's psychosocial development in order to integrate the family system into the treatment model (Sherwen & Boland, 1994; Stuber, 1992). Family-centered treatment is individualized according to the patient's developmental stage and personal needs, but is understood within the dynamic family context. The needs and role of siblings should also be considered by health care providers when planning a treatment strategy for a family affected by pediatric AIDS (Fanos & Weiner, 1994). Family-focused services also include comprehensive medical treatment, community agencies, and coordinated case management, acknowledging a broad view of a "family" system (Boland, Czarniecki, & Haiken, 1992). Pediatric AIDS patients may also benefit from family-focused mental health services. For example, one study of family-focused mental health services reduced isolation, improved family functioning and encouraged the use of other services such as respite care (Mellins & Ehrhardt, 1994).

Disclosure

There is no single, easy guide to deciding when and to whom HIV infection should be disclosed. Several im-

portant issues inhibit disclosure and others promote it. Disclosure may cause a child to become distressed and anxious. Therefore, HIV serostatus is often withheld from children because parents and guardians fear that such information may cause depression and a decline in health (Lewis et al., 1994). When children are told about their infection, they commonly ask questions such as "am I gonna die?" and "why me?" (Stuber, 1992). For many families, taboos such as illegal drug use and sex, which are inextricably linked to HIV, complicate the question of whether disclosure will be beneficial to the child (Lipson, 1994). However, for some children whose HIV infection is not known outside the family, the burden of secrecy may promote feelings of isolation and hinder healthy development (Fanos & Wiener, 1994). The literature on chronic illnesses suggests that disclosure of the developmentally appropriate facts about illness improves the child's psychological adaptation. When dealing with a disease such as cancer, for example, disclosure has been found to reduce the child's feelings of distrust, isolation, confusion, and depression (Lipson, 1994). Finally, cultural differences may influence motivations for disclosure and secrecy. Cohen (1994) found that most African-American primary caregivers disclose their HIV-infected child's serostatus to immediate family members, whereas in the United Kingdom, where HIV is more stigmatized, only a minority of families with HIV-infected children disclose to their close relatives.

The issue of disclosure for children and adolescents with HIV is complex and multi-faceted, interrelated with other psychiatric and psychosocial concerns. HIV infection carries stigma and shame, impacting the family, school, community, and institutional network of relationships. Stigma and shame lead to further ostracism and the child's sense of emotional wellbeing and competence can be further impaired. Case reports on disclosure in children of infected parents suggest that less secrecy about HIV helps children feel less shame and may lead to more intimate family relationships (Siegel & Gorey, 1994). However, disclosure should take place in a setting where parents and health professionals work together. For this purpose, family-centered and multidisciplinary approaches to caretaking are particularly useful. Brown and DeMaio (1992) describe two HIV-infected adolescents with hemophilia to illustrate how, if not properly managed, secrets concerning infection may interfere with optimal health care and the patient's subsequent emotional adjustment.

Multiple Losses and Bereavement

Children and adolescents with HIV have to cope with their own mortality but also often have loved ones with HIV or AIDS (Roth, Siegel, & Black, 1994). Children and adolescents who have recently lost a family member may have symptoms of depression, suicidality, somatization, and conduct disturbance in addition to poor academic performance and low self-esteem (Rotheram-Borus, Murphy, Miller, & Draimin, 1997). These symptoms exist in part because the children and adolescents may not have the support of their grieving or ill parents (Fanos & Wiener, 1994). Bereavement is made more difficult due to social stigmas. Grief which cannot be expressed due to fears of stigmatization or ostracism has been termed disenfranchised grief and may worsen the symptoms of mourning (Siegel & Gorey, 1994). In addition, mourners may be deprived of the usual buffering social supports as

a result of fear of stigmatization. The secrecy surrounding the death of a parent due to AIDS may lead the children to believe that the death was shameful. Ostracism or taunting by family and classmates may exacerbate the shame and impair a child's sense of emotional wellbeing, social competence, and achievement (Siegel & Gorey, 1994).

Interventions are needed to improve the adaptation of young people with HIV who are forced to confront death and dying (Grassi et al., 1998). If possible, it is necessary to elicit the support of members of the patient's extended family in coping with these problems (Mellins & Ehrhardt, 1994). Multiple factors put some families at higher risk and make other families more resilient (Christ, Siegel, Mesagno, & Langosch, 1991). As part of the process of helping families to cope with death and become more resilient, several psychosocial risk factors need to be identified. In addition to the limitations and multiple losses of parents of HIV-infected children, the grandparents may be limited in their ability and willingness to raise a second family (Boland et al., 1992; Hardy et al., 1994). Effective interventions ensure that the caretaker is someone with whom the child may effectively bond and who will reciprocate the attachment (Aronson, 1996). Treatment strategies for families affected by pediatric HIV should also target siblings (Fanos & Wiener, 1994). Siblings may become surrogate parental supports in the absence or death of the child's parents or, conversely, they may present an additional stress or source of trauma and bereavement. The loss of parental support may also force older siblings to leave school in order to take care of younger siblings (Rotheram-Borus et al., 1997).

One important issue in psychotherapy with HIV-infected children who have experienced the loss of a parent or sibling to AIDS is the need to express their fears and fantasies. In the absence of open communication, pathological grief reactions may develop (Siegel & Gorey, 1994). Often before a therapeutic relationship can be established with the infected child, the family has to cope with anger towards the infected parent (Sherwen & Boland, 1994). Unresolved anger directed against the infected parent or toward the infected child may inhibit communication and undermine emotional support for the child. Further research is required to examine the characteristics of different family structures and how they may affect the psychosocial development of the infected child.

A structured program to deal with the issues surrounding death and dying for adolescents who have a parent living with HIV/AIDS has been described by Rotheram-Borus et al. (1997). Their cognitive-behavioral intervention includes workshops that focus on behavioral and coping skills to help parents to adapt to the illness and disclose serostatus to the family. The program addresses the adolescent's reaction to the parent's illness, assists in planning for the eventual death of the parent, and deals with bereavement after the parent dies. This model has borrowed from other therapeutic interventions for families coping with chronic and terminal illnesses, such as psycho-educational programs that offer support to children of families in which one parent has advanced cancer (Christ et al., 1991).

Multidisciplinary Services

Many common HIV-related symptoms and physical limitations reported by young patients are emotionally

based, yet relatively few clients obtain mental health or case management services (Ammann, 1994). For example, in the University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program, most symptoms and limitations were diagnosed as affective, rather than organic (Remafedi, 1998). Relatively few clients had obtained mental health or case management services before their involvement with this initiative. An ideal treatment model for children and adolescents living with HIV would be the integration of medical, psychological, and social services by both primary clinicians and community-based outreach staff. At its most expansive, this perspective requires the cooperation of pediatricians, social workers, psychologists, psychiatrists, a medical ethicist, a psycho-educational specialist, occupational, physical, and language therapists, and case managers (Hopkins, Grosz, Cohen, Diamond, & Noyce, 1989). In a multidisciplinary treatment approach, the psychosocial elements that influence symptoms and medical treatment outcome are identified and addressed.

Examples of programs that offer multidisciplinary services for HIV-positive children and adolescents are the 10 service projects of the SPNS Program, funded by the Health Resources and Services Administration (E. R. Woods, 1998). These multidisciplinary programs attempt to offer affordable yet comprehensive medical and psychosocial services including counseling, group support, and case management. Multidisciplinary pediatric and adolescent AIDS care requires intensive youth participation, outreach, case management, linkage to services, and comprehensive continuum of care, all integrated in the context of primary care clinical programs. One program in California, the Walden House, offers medical and psychological assessment, referral and coordination of care, therapy and counseling, transportation, peer education, legal information, and long-term management options for HIV-positive adolescents (Hymel & Greenberg, 1998). Other programs offer similar services but provide differing degrees of integrated treatment and community outreach (Bettencourt, Hodgins, Huba, & Pickett, 1998; E. R. Woods et al., 1998). There are obvious economic and institutional barriers to the provision of expansive multidisciplinary services on a widespread basis. In practice, the multidisciplinary model has been often limited to experimental programs, research programs, and Title IV demonstration projects. More often, this model is embodied in a somewhat less comprehensive but effective program of family-centered services. These programs attempt to complement primary care and social services with family therapy.

Provider issues. Health care workers of HIV-infected youth face the challenges and stressors of dying patients, families in conflict, a constantly changing science, and often inadequate treatment resources. Research is just beginning to examine the impact of these stressors on health care workers and the results, thus far, are provocative. Numerous case reports document the types of stressors for workers and suggest interventions such as further training, peer support, and increased resources (Barbour, 1994; Silverman, 1993). Although cross-sectional surveys report substantial distress and the emotional difficulties of this intense level of care, the few reported rates of burnout or job attrition are comparable to health care workers in other settings (Miller & Gillies, 1996). One report found that burnout, as defined by the Maslach Burnout Inventory (Maslach & Jackson, 1986), was 7.4% among a nationally representative sample of

professionals working with patients with HIV and hemophilia (Brown, Stermck, Ford, & Geary, 1999). A job attrition rate of 35% per year over the next 4 years, was associated most with perception of difficulties with colleagues rather than specific job tasks, patient care characteristics, or training experiences (Brown et al., 1998). These data suggest the important role that a well-functioning treatment team has in buffering the inevitable stress of complex patient care and indicate the important role of mental health providers in liaison activities.

Conclusions

In the third decade of HIV, research will offer a more complete understanding of the virus, its biology, and its treatment. Research should increasingly emphasize areas of importance to the understanding of HIV in children and adolescents. First, the implications of HIV as a subacute, chronic disorder, rather than as a lethal illness, will be clarified. Second, the results of research trials on adults will be systematically understood and applied to the unique needs and biology of children. This application is especially important in the use of multi-drug therapies. Third, data will emerge concerning the effective elements of psychosocial treatment for the multiple contexts in which HIV occurs within families.

HIV as a Chronic Disorder

The transition from an acute, lethal disease to a subacute, chronic disease has enormous implications for the neurocognitive and emotional development of children. As children born with HIV will continue to live longer, normal developmental milestones and educational needs will take on new significance. The mental health needs of those born with HIV and those acquiring the virus later may become even more disparate and may need to be studied independently. The impact of prolonged quiescent disease on perception by the self, family, society, and culture at large could be dramatic and longitudinal studies need to be pursued. Research also needs to be directed at quality of life and other psychological concerns. Adherence will continue to be an increasingly important treatment concern as even more effective medical treatment regimens evolve. Unfortunately, most medical care systems are more suited to acute, curative interventions rather than chronic, subacute care. Lessons from other chronic diseases will prove helpful. In other chronic diseases such as cancer, patients and even survivors may develop secondary illnesses in response to the treatments. In turn, future psychosocial research into HIV as a chronic disease may examine problems whose solutions will benefit the care of other chronic disorders. Current psychiatric diagnostic categories are criticized for only being partially relevant to the emotional disorders found in children and adolescents with chronic illnesses. Current standardized instruments are not designed for persons with brain disorders or chronic illness, hence the responses of children with HIV infection may be misinterpreted. HIV research that finds more appropriate schemas for these disorders will have broad implications.

Pediatric-specific Moderators and Therapies

A second area of major research will focus on modifying standard HIV treatments, once they are established, specifically for children and adolescents. The mechanisms

of HIV pathophysiology may be quite different in an evolving organism with a potentially long life span. In fact, the assessment of HIV in children over time will provide insight into the relationship between cognitive development and brain growth during childhood. Multi-center drug trials in children and adolescents follow adult trials but are smaller in number and may reveal differences in dosing and susceptibility, since a developing immune system may be more vulnerable to retroviral infection. For example, HIV dementia progresses more rapidly in infants, possibly related to infection during critical windows in early development. Another example of childhood-specific factors in infection is the evidence that adolescent girls may be especially vulnerable to HIV infection through heterosexual transmission because of their immature cervical mucosa and hormonal changes at the time of exposure (Minkoff, DeHovitz, & Duerr, 1995). Other factors such as nutrition, especially the role of vitamins, ethnicity, and even geography may have additive influences in children that are not yet understood. Changes in Food and Drug Administration guidelines to promote research in children should help to illuminate the efficacy of specific treatments in children and adolescents. Much basic and clinical research is needed to determine when to initiate and modify therapies, which drug combinations are safe and feasible, how to measure treatment failures, and what long-term adverse physiologic and psychological affects arise after years of treatment (Carpenter et al., 1998).

Elements of Effective Psychosocial Treatment

There is an obvious need to pool medical and psychological information from multiple sites, since each center's experience is limited. Although data on psychological distress has been described, and documented rates of psychiatric disorder in adults with HIV is 31–65% (Gonzalez & Everall, 1998), the prevalence rates of psychiatric disorders in HIV-infected children and adolescents is unknown. Researchers have shied away from imposing further stigmatizing psychiatric labels, especially in adolescents, but miss the opportunity to offer accepted and beneficial treatments such as antidepressants, stimulants, and mood stabilizers to affected young people. The use of standardized instruments for childhood disorders may be particularly helpful in identifying psychiatric disorders in these groups. Although the use of standardized clinical instruments may improve the objectivity of reporting, it may lead to the inclusion of "psychiatric symptoms" of adaptation to illness that are not evidence of a "disorder" or are unrelated to psychiatric disorders. As with other chronic illnesses, inattention and hyperactivity may be due to medication side effects or medical causes other than ADHD. Further work is therefore needed to modify standardized instruments for children with HIV and other chronic illnesses. The elements and modalities of effective multidisciplinary treatment that are responsible for its impact need to be determined. Clarifying effective treatments is an important opportunity for child and adolescent psychiatrists and psychologists, since creating successful family therapy for HIV-infected children and their families has been a challenge for health care workers. Barriers have included a lack of consensus on what constitutes a "family," lack of cultural sensitivity to different patterns of social support, lack of longitudinal family studies, limitations of cross-sectional studies on the impact of

illness on family, and lack of research in developing countries (Bor & du Plessis, 1997). Given the difficult circumstances that surround individuals with HIV/AIDS, such as poverty and stigma, clinicians must often be the ones to initiate care for the affected family and actively demonstrate their acceptance and commitment to the treatment. This active approach is quite different from the routine care offered to patients with greater personal and financial resources. It is assumed that families require access to basic services, appropriate medical care and an active, psychosocially oriented provider. Beyond these minimal elements, it is unclear which approach is likely to be most effective in what context. Multidisciplinary treatment should continue to be the goal, although treatment must be locally relevant to be effective. Thus, some disciplines and resources may be most useful at certain treatment sites.

Child and adolescent psychiatrists and psychologists are needed to identify and treat youth impacted by HIV and to guide preventative interventions. Necessary consultation and liaison activities include assistance in organizing psychologically appropriate multidisciplinary treatment, attention to the mental health needs of providers, and advocacy efforts to address the co-occurring social factors. As advocates, child and adolescent psychiatrists and psychologists can extend efforts to many organizations, such as school systems struggling with the treatment of HIV-infected youth, community-based agencies implementing HIV prevention programs, and state agencies concerned with the accessibility of health care.

In summary, HIV is likely to continue to concern child and adolescent mental health providers in the next decade. Fortunately, there is much to be learned from research on HIV in adults, experience with other pediatric chronic diseases, and emerging research in the biopsychosocial aspects of HIV in children and adolescents. These data provide a solid approach for identifying relevant disorders, enhancing medical care and promoting successful adaptations of patients and families. Future research and clinical experience can be instrumental in improving the psychosocial treatment of children and adolescents living with HIV. Successful treatment will not only ameliorate the burden of patients and families, but also will have broad implications for youth impacted by other chronic diseases.

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