

# Youths and HIV/AIDS: Psychiatry's Role in a Changing Epidemic

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## ABSTRACT

**Objective:** To review the past 10 years of published research on human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) in the United States, including psychosocial and psychiatric risk factors, epidemiology, biology, neurocognitive and psychiatric sequelae, disclosure issues, prevention strategies, and biological and behavioral treatments. **Method:** Researchers reviewed the English-language literature with a focus on child and adolescent risk factors associated with HIV/AIDS, prevention, and treatment. **Results:** Substantial scientific advances have occurred over the past two decades leading to decreased morbidity and mortality in the United States from AIDS-related opportunistic infections. At the same time, rates of HIV infection are increasing in teenagers, young women, and minorities, and growing numbers of youths are living with an infected family member. Understanding HIV risk behavior requires a broad theoretical framework. Comprehensive HIV prevention programs have led to reduced risk behavior among HIV-affected youths and teens at risk of infection. Biological and behavioral treatments of HIV infection continue to evolve and have led to longer life span, improved quality of life, and fewer psychiatric problems. **Conclusions:** HIV/AIDS has significant mental health implications, and psychiatry can play a critical role in curbing the epidemic. With minimal effort, mental health professionals can adapt and apply the strategies that they use to treat psychiatric symptoms to prevent HIV transmission behaviors. *J. Am. Acad. Child Adolesc. Psychiatry*, 2005;44(8):728–747. **Key Words:** human immunodeficiency virus/acquired immunodeficiency syndrome, psychosocial, psychiatric, prevention, treatment.

In the past 10 years, there have been dramatic shifts in the fight against human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). We have witnessed significant progress in understanding the mechanisms of HIV transmission and prevention and the development of more sophisticated systems for classifying AIDS and its associated syndromes. The variety

of treatments available for HIV-infected individuals has transformed the disease from certain death to a chronic medical illness. The rate of AIDS deaths has decreased, and the epidemic has slowed in some regions of the United States. Despite these important advances, new groups are now at the forefront of the disease, including youths and women (Centers for Disease Control and Prevention, 2000). There is still no cure, and behavioral prevention remains the most viable strategy to reduce the spread of infection. Thus, HIV prevention has emerged as one of the greatest national public health priorities.

Three groups of young people are most affected by HIV: those born with the infection, those who acquire HIV through risky sexual behavior and drug use, and those whose parents or family members are infected. There has been a dramatic decrease in the number of new cases of vertically transmitted HIV in the United States during the past 10 years, but children infected at birth or through blood transfusions are surviving into adolescence and becoming sexually active. These teens have significant psychiatric issues as a result of living

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with a chronic medical illness and present a host of challenges for mental health professionals. Most young people today acquire HIV through unprotected sexual intercourse and other high-risk sexual behavior, such as sex with multiple partners and frequent sexual activity (Centers for Disease Control and Prevention, 2000; Howard and Wang, 2004). Finally, growing numbers of youths are living with infected family members as new treatments extend the lives of people with HIV/AIDS. For these youths and families, concerns related to stigma, appropriate disclosure, and medication adherence are central.

In this 10-year review, we offer a social-personal framework to explain HIV risk behavior among teens and review the epidemiology, biology, and neurocognitive development of HIV and AIDS. We present the most current definitions and approaches to disease diagnosis and review neurocognitive and psychiatric problems associated with HIV disease. We also review key issues facing young people affected by HIV/AIDS in a family member. We describe current treatment options for infected youths and promising HIV prevention and intervention programs. HIV is a prototypical disease for mental health professionals to understand the interplay among biological, genetic, and environmental factors. Mental health professionals, because of their access to families and youths, are uniquely positioned to reduce HIV transmission by using therapeutic strategies to teach important HIV prevention skills.

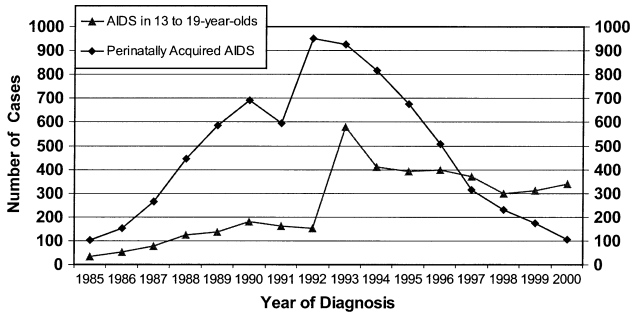
### HIV/AIDS EPIDEMIOLOGY

Despite lower rates of vertical transmission over the past decade, the number of infections acquired during adolescence is increasing. Of the estimated 40 million people living with HIV/AIDS worldwide, 2.5 million are children younger than 15 years old (Joint United Nations Program on HIV/AIDS and World Health Organization, 2003). At the end of 2002, there were 9,300 cases of AIDS in children younger than age 13 years in the United States, but many more youths were infected. Teenagers account for 50% of new HIV infections and 25% of new sexually transmitted diseases (STDs) reported annually (Centers for Disease Control and Prevention, 2000), but all groups are not affected equally; 61% of infections occurred in females, and among the 13- to 19-year-olds, 56% were African

Americans (Centers for Disease Control and Prevention, 2000). Figure 1 illustrates the shifts in pediatric and adolescent-acquired HIV infection during the past 20 years. Demographic data on ethnicity, gender, mode of transmission, and location by cities and states for pediatric and adolescent AIDS can be found at: <http://www.cdc.gov/hiv/graphics/pediatri.htm> and <http://www.cdc.gov/hiv/graphics/adolesnt.htm> (both accessed June 25, 2004).

In the United States alone, 110,000 youths represent 18% of the people living with HIV (Centers for Disease Control and Prevention, 1998a). Despite lower rates of vertical transmission, perinatally infected youths are becoming sexually active as they reach adolescence, and a growing number of pregnancies have been reported in vertically infected females in the United States and Puerto Rico (Centers for Disease Control and Prevention, 2000). Data from seropositive adults and youths suggest that about one third continue their transmission behaviors (unprotected sexual intercourse and intravenous drug use) after learning that they are HIV positive (Hein et al., 1995). Thus, infected teens are placing themselves, their partners, and their offspring at significant risk of infection and reinfection with new viral strains.

HIV also represents an enormous burden for affected family members (Pequegnat and Szapocznik, 2000). The number of U.S. children and adolescents affected by HIV in a family member is growing because the majority of infected women are mothers (Rotheram-Borus et al., 2003; Schuster et al., 2000); 60% have children younger than age 18 and 45% are living with their children. Most of these children are uninfected themselves (Bauman et al., 2002) yet remain with their infected parent regardless of the severity of the parent's illness (Schuster et al., 2000). In one study, more than half of the parents living with their children had symptomatic HIV, and 30% were diagnosed with AIDS (Schuster et al., 2000). Globally, more than 14 million children have been orphaned by AIDS (UNICEF, 2004). Almost half of orphaned children are between 11 and 17 years old (Leibowitz et al., 2000). Orphaned children are less likely to complete their education and more likely to be involved in child labor, encounter stigma, and suffer sexual and physical abuse (UNICEF, 2004). Thus, children of infected family members confront a host of consequences that place them at risk of adverse outcomes (Armistead and Forehand, 1995).



**Fig. 1** Perinatally acquired and adolescent (13–19 years old) AIDS cases, by year of diagnosis, 1985–2000, United States (Centers for Disease Control and Prevention, 2001).

### YOUTHS AT RISK OF HIV/AIDS

The primary risk for acquiring HIV/AIDS during adolescence comes from high-risk sexual behavior and drug use. Typical behaviors initiated during adolescence increase risk, such as sexual and drug experimentation, but little is known about the causal mechanisms associated with these behaviors among young people. Youths with mental health problems are at even greater risk of exposure because they engage in the same behaviors as their school-age peers but at higher rates (Brown et al., 1997a; Donenberg et al., 2001). Specifically, when compared with youths attending public schools, psychiatrically hospitalized teens are twice as likely to be sexually active, twice as likely not to use condoms, and more than twice as likely to use intravenous drugs (DiClemente and Ponton, 1993). Teens in inpatient psychiatric care also engage in more self-cutting and sharing cutting utensils than nonpsychiatrically ill youths (DiClemente et al., 1991), and adolescents with psychiatric disorders are more likely to have a history of STDs than youths without psychiatric disorders (Baker and Mossman, 1991). Teens in outpatient mental health care also report high rates of HIV/AIDS risk behavior, including sexual intercourse (54.7%) and having been pregnant (8.3%). Among sexually active teens in outpatient psychiatric care, 22% report early sexual initiation ( $\leq 14$  years old), 12.8% report having had an STD, 48.9% report using drugs/alcohol while having sex, and 55.3% report having had sex without using a condom (Donenberg et al., 2001, 2003). Early sexual debut increases risk of infection because of added opportunities for sexual encounters and multiple partners. Finally, as many as 30% of youths with psychiatric disorders report comorbid substance abuse (Arrufo et al.,

1994), and alcohol and drugs interfere with safe decision making and effective management of affective arousal.

Understanding the processes associated with HIV transmission among teens with mental health problems requires a broad contextual framework that includes individual and social factors. A social-personal framework of HIV risk behavior among teens in psychiatric care includes maturational constructs implicated in adolescent risk taking (e.g., pubertal development, perceptions of immortality, identity exploration, limitations in abstract thinking) and key psychosocial and contextual risk factors (Fig. 2). The model underscores the interplay of four factors described below: personal attributes, family context, peer and partner relationships, and environmental circumstances (Donenberg and Pao, 2003).

### HIV Risk and Personal Attributes

Personal attributes implicated in adolescent risk behavior include cognitions about HIV/AIDS (knowledge, attitudes and beliefs, impaired decision making), affect dysregulation, mental health problems (internalizing and externalizing), history of sexual abuse, and personality traits (sensation seeking, achievement orientation, value on health).

*Cognitions.* Adolescents generally report accurate information about HIV/AIDS (e.g., cause of infection, modes of transmission and prevention), but increasing knowledge has not altered sexual risk taking (Morrison-Beedy et al., 2003). Positive attitudes and beliefs about HIV prevention, however, are related to health-promoting behavior. Perceptions of personal vulnerability, motivation to prevent transmission, and behavioral intentions to practice safer sex are among some of the cognitive factors that predict safe sex behavior among youths (Fisher and Fisher, 1995; Katz et al., 1995; Lawrence, 1993). Greater self-efficacy to use condoms is associated with delayed sexual debut (Santelli et al., 2004).

Many teens in psychiatric care have important cognitive deficits that place them at elevated risk of exposure to HIV. Dysfunctional thinking about relationships and problems in accurate judgment interfere with their ability to assess risk and lead to poor decision making, diminished problem solving, and poor reality testing (Brown et al., 1997a). Although perceptions of self-efficacy to practice prevention are linked to less risky

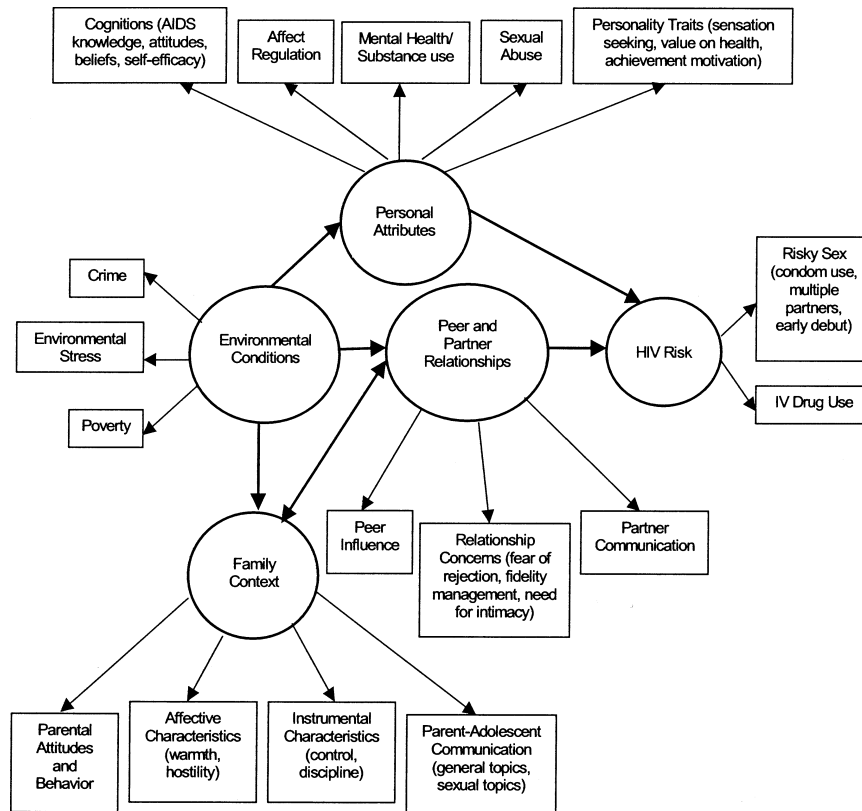


Fig. 2 The social-personal model.

behavior, many youths with psychiatric problems lack the self-confidence and interpersonal and social skills (e.g., assertiveness, effective communication) necessary to negotiate safe sex practices (Brown et al., 1997b; Carey et al., 1997). Thus, sexual behavior among teens in psychiatric care is more likely to be impulsive and spontaneous and not the result of calm decision making (Donenberg et al., 2005).

*Affect Dysregulation.* Affect regulation skills facilitate successful coping with distress and may help reduce risk behaviors (DiClemente et al., 2001). Poor affect regulation limits teens' ability to weigh the pros and cons of using risky sex to obtain short-term relief, thereby increasing their risk of HIV infection (Cooper et al., 2003). Moreover, deficits in emotion regulation are associated with mental health problems, such as conduct disorder and depression (Catanzaro, 2000; Eisenberg et al., 2001). Many youths in psychiatric care experience high levels of negative emotional arousal and lack effective emotion regulation skills. Instead, they respond impulsively to negative arousal to decrease distress. Individuals who lack a cognitive link between the negative

stimuli and their impulsive action are unable to weigh the risks/benefits of sex or to plan for protective behavior. Alternatively, these teens adopt short-term self-soothing behaviors (e.g., risky sex, sharing cutting utensils) over self-regulation (Tice et al., 2001). Distress and anxiety in sexual situations may be particularly stressful for these youths because of relationship maintenance concerns (e.g., "What if my partner rejects me?") or previous trauma. Emotion regulation can be influenced through learning and modeling, especially in a therapeutic context (Cicchetti et al., 1995).

*Mental Health Problems.* Two categories of mental health problems, externalizing (e.g., aggression, delinquency) and internalizing (e.g., depression, anxiety), are differentially linked to HIV risk behavior (Donenberg et al., 2001; Tubman et al., 2003). Youths with externalizing problems engage in a broad array of risky behaviors, including frequent sexual activity, early sexual debut, low rates of condom use, high numbers of sexual partners, and high rates of prostitution, drug use, needle sharing, exchanging sex for drugs, and drug/alcohol use before and during sex (Koopman et al., 1994;

Rotheram-Borus and Koopman, 1991; Stiffman and Cunningham, 1991). Additional risks come from inadequate sexual communication skills and susceptibility to peer norms that encourage deviant sexual behavior. Internalizing problems are also related to HIV risk, including low perceived self-efficacy, decreased assertiveness, and minimal ability to negotiate safe sex with a partner (Brooks-Gunn and Paikoff, 1997; Brown et al., 1997a). Depression and low self-esteem are linked to sexually permissive attitudes, having sexually active friends, low contraceptive use, high risk of pregnancy, and nonvirgin status (Dolcini and Adler, 1994; Rotheram-Borus et al., 1995; Whitbeck et al., 1993). Risk may not be uniform across mental health problems, however. Hospitalized teens with conduct disorder report higher rates of risk behavior than do teens with an affective disorder (DiClemente et al., 1989), and Donenberg et al. (2001) found that externalizing but not internalizing problems were linked to greater sexual risk taking and substance use.

*Sexual Abuse.* Childhood sexual abuse is consistently associated with elevated rates of HIV risk behavior (Brown et al., 1997b, 2000). Sexually abused youths report earlier sexual debut, more frequent sexual activity, less consistent condom use, lower self-efficacy for condom use, increased concern with conforming to peer sexual norms, anxiety about partner rejection, and more lifetime sexual partners than nonabused peers (Lodico and DiClemente, 1994). Abused youths are more likely to have gotten someone pregnant or to have been pregnant and to have engaged in coercive sex (Brown et al., 1997b). In role-plays, abused teens lacked appropriate assertiveness by communicating their views less consistently, clearly, and directly than nonabused teens. Deficits in sexual communication may reflect abused teens' fear of partner rejection, feelings of powerlessness, and general passivity in relationships (Brown et al., 2000).

*Personality Traits.* Three personality traits are particularly relevant for adolescent risk behavior, value on health, sensation seeking, and achievement motivation. Greater health concerns are associated with decreased risk behavior (Costa et al., 1996), and youths' reported value on health predicts delayed sexual intercourse with new partners (Rosengard et al., 2004). Sensation seeking or the willingness to take physical and emotional risks to obtain novel and complex experiences is associated with inconsistent condom use, behavior problems

among youths (Brown et al., 1992; Zuckerman, 1994), and more sexual partners and unknown sexual partners among adults (Fisher and Misovich, 1990). High sensation seekers are more likely than low sensation seekers to have had sex, had unwanted sex, and used alcohol or marijuana (Donohew et al., 2000). Negative attitudes about school, poor academic performance, and low achievement motivation are related to risky sexual behavior (Kirby, 2002b). High achievement motivation, positive school involvement, and strong academic performance are linked to delayed sexual debut, increased contraceptive use, and decreased rates of pregnancy and childbearing (Brooks-Gunn et al., 1993b; Resnick et al., 1997).

#### HIV Risk and Family Context

A large body of research documents a central role of parents and families in adolescents' sexual values, attitudes, and behavior (Crosby and Miller, 2002; Perrino et al., 2000). The family is the primary source of sexual socialization for children (Fisher and Feldman, 1998; Perrino et al., 2000). Four areas of family functioning are consistently related to youths' sexual risk taking and attitudes: affective characteristics (warmth, support, hostility), instrumental characteristics (monitoring, supervision, control), parent-adolescent communication, and parental attitudes and behavior.

*Affective Characteristics.* Family affective characteristics can mitigate high-risk behavior among teens. Family availability, support, connectedness, and cohesion; high relationship satisfaction between mothers and adolescents; and low parental hostile control and family conflict are all related to reduced sexual experience, less risky sexual behavior, increased use of birth control, and delayed sexual debut (Borawski et al., 2003; Donenberg et al., 2003; McBride et al., 2003; Miller et al., 2001).

*Instrumental Characteristics.* Parental monitoring, supervision, strictness/missiveness, and involvement are also linked to teens' sexual experience and sexual risk taking. Parental monitoring lessens youths' opportunities for sexual activity (Paikoff, 1995), predicts less risky sex (Metzler et al., 1994), and reduces other high-risk behaviors that often co-occur with risky sex, such as drug and alcohol use and delinquency. In one study, however, negotiated unsupervised time (knowing with whom and where the adolescent would be) was related to both safer sex behavior *and* increased risky sexual

activity (Borawski et al., 2003). These data suggest that negotiation may be less important than actual supervision in reducing risk taking. Among teens in psychiatric care, greater parental monitoring and supervision and less parental permissiveness are related to reduced sexual risk taking, but links are stronger for girls than for boys (Donenberg et al., 2002).

*Parent-Teen Communication.* Parent-teen communication about sex influences adolescent sexual behavior (DiIorio et al., 2003; Jaccard et al., 2000). Studies are mixed, however, and suggest that more frequent communication is related to both more and less risk taking (Miller et al., 1998; Whitaker and Miller, 2000). There is evidence that the quality of communication matters more than frequency (Wilson and Donenberg, 2004). For example, positive parent-teen communication (open, receptive, comfortable) about sexual topics is related to less sexual experience and reduced risky sexual behavior among adolescents (Hutchinson et al., 2003; Miller et al., 1998). There may be a unique relationship between sexual risk taking and parent-teen communication for teens in psychiatric care. Wilson and Donenberg (2004) found higher rates of risky sexual behavior among teens in which the parent-teen communication was characterized as more mutual or in which parents tended to act more like peers than authority figures. Moreover, those teens whose parents disagreed with them (i.e., behavior that was intended to correct or change the adolescents' actions or opinions) and were more directive (i.e., parents behaved in a demanding or dominant manner) reported less sexual risk taking. Appropriate intergenerational boundaries (Minuchin, 1974), absent in many families in psychiatric care, may be critical to preventing adolescent risk taking.

*Parental Attitudes and Behavior.* Parents influence youths' sexual health and development through modeling and example (Jaccard and Dittus, 2000; Wickrama et al., 1999). Mothers' sexual behaviors are associated with sexual risk taking by their daughters (Kotchick et al., 1999), and, compared with women who were older at first childbirth, teen mothers are more likely to have daughters who are sexually active as adolescents (Hardy et al., 1998). Daughters of teen mothers often become teen mothers themselves (Serbin et al., 1998). Perceptions of maternal approval of birth control are related to increased likelihood of sexual initiation and birth control use (Jaccard and Dittus, 2000), and perceptions of parental disapproval of teen sex are related

to delayed sexual debut, fewer partners, and decreased sexual activity and teen pregnancy (Meschke et al., 2002; Miller et al., 1999).

#### HIV Risk and Peer and Partner Relationships

Peers and romantic partners become increasingly important during adolescence. Three areas of peer and partner relationships are especially salient for adolescent risk behavior: relationship concerns, peer influence, and partner communication.

*Relationship Concerns.* Romantic relationships often produce intense fears of rejection and abandonment (Welsh et al., 2003). Responsible sexual behavior, such as abstinence or condom use, is a potential source of conflict with and even rejection by romantic partners (Eyre et al., 1998). Thus, safer sex may be a low priority for teens who believe that maintaining relationships is more important than preventing HIV. Evidence of this is particularly strong for girls and women (Eyre et al., 1998). Desire for intimacy, love, and affiliation has been linked to sexual behavior among boys and girls (Ott et al., 2004; Sanderson and Cantor, 1995) and a primary reason for first sexual intercourse (Rodgers, 1996). Eyre et al. (1998) found that adolescent girls believed asking a partner to use a condom would endanger the trust between partners. It is less clear whether the same concerns exist for boys. Pressure to maintain relationships to meet intimacy needs may be particularly powerful for youths in psychiatric care because they tend to have strained, conflictual, and unsupportive relationships with family, peers, and partners (Brown et al., 1997a; Seefeldt et al., 2003). These teens may respond less assertively to partner pressure to avoid disconnection (Donenberg et al., 2001; Welsh et al., 2003).

*Peer Influence.* The desire for conformity peaks during adolescence, and peers are an important source of sexual information. Adolescent sexual behavior often reflects perceptions of normative peer behavior, including decisions to use birth control and condoms, early sexual initiation, and oral sex (Kinsman et al., 1998; Prinstein et al., 2001). In one study, positive peer norms about abstinence were the single best predictor of delayed sexual initiation among middle school students (Santelli et al., 2004). Among youths in psychiatric care, Wilson et al. (unpublished, 2004) found that more negative peer influence (i.e., peer support and approval of high-risk behavior, including drinking alcohol, smoking marijuana,

smoking cigarettes, and having sex) was associated with less likelihood of using a condom and increased likelihood of having sex while using drugs/alcohol. Negative peer influence has been strongly associated with risky sex among youths in outpatient psychiatric care and mediated links between psychopathology and risk (Donenberg et al., 2001). Moreover, peer influence is highly correlated with alcohol and drug use (Donenberg et al., 2001), and substance use is associated with increases in risky sexual behavior.

*Partner Communication.* Assertive communication with sexual partners is essential to practice safe sex, but teens often have difficulty communicating assertively and negotiating safe sex practices (Crosby et al., 2003; Hutchinson and Cooney, 1998; Whitaker et al., 1999). Communication between teenage sexual partners is related to less sexual risk taking, more HIV prevention self-efficacy, fewer partners, and more consistent condom use (Hutchinson and Cooney, 1998; Tschann and Adler, 1997; Whitaker et al., 1999). Teens who express a desire to use condoms to their partner are more likely to use them, and youths who discuss their sexual history have fewer partners. Adolescents who feel confident about initiating safer sex discussions with a partner are also more likely to use a condom and/or resist pressures to engage in high-risk sex in real sexual encounters (Lawrence, 1993). Unfortunately, those teens in psychiatric care who are more vulnerable to rejection will avoid these discussions for fear of losing the relationship, thereby placing themselves at even greater risk of exposure. Moreover, mental health problems reduce effective communication and self-assertion with peers and partners (Brown et al., 1997a).

#### HIV Risk and Environmental Circumstances

Environmental factors shape adolescent sexual behavior. Neighborhood disadvantage (e.g., poverty, violence), ethnic composition, exposure to community violence, neighborhood disorganization (e.g., physical deterioration, drug trafficking), and stressful life events (e.g., divorce) are associated with early sexual initiation, multiple sexual partners, premarital childbearing, increased sexual activity, and greater permissiveness (Brooks-Gunn et al., 1993a; Ramirez-Valles et al., 2002; Sucoff and Upchurch, 1998). Some studies suggest, however, that environmental context explains only a small fraction of the problem (Blum et al., 2000; Santelli et al., 2000). Nevertheless, the presence of supportive family or other adult relationships (e.g., teacher, counselor, aunt), com-

mitment to education, and consistent involvement in church activities (Hawkins et al., 1992; Wills et al., 1992) can mitigate the impact of environmental stress on sexual risk taking.

Taken together, the research supports a broad social-personal framework of HIV/AIDS risk among youths with mental health problems. This model offers several directions for HIV prevention targets to reduce transmission behaviors and underscores the need for programs to address a multitude of factors that affect risk.

#### YOUTHS AFFECTED BY HIV/AIDS

HIV still carries significant stigma and ostracism for those associated with the disease. Despite growing numbers of youths affected by HIV/AIDS, there are relatively few empirical data on the impact of living with an infected family member or potential risk and protective mechanisms for these children and adolescents. Most of the studies have examined the impact of maternal HIV disclosure on youths, the mental health and behavioral consequences of young people affected by HIV/AIDS, and specific factors related to negative and positive outcomes, including family processes, financial resources, and social support.

##### Maternal HIV Disclosure

The impact of maternal HIV disclosure on youths is unclear. Some studies reveal no discernible effect on children's psychological functioning (Armistead et al., 2001; Bauman et al., 2002; Murphy et al., 2002a), whereas others indicate increased emotional distress and behavior problems (Lee and Rotheram-Borus, 2002; Lee et al., 2002; Shaffer et al., 2001). One study revealed elevated sexual risk taking, substance abuse, and emotional distress among teens who were told their mothers' HIV status compared with uninformed youths (Rotheram-Borus et al., 1997), but Armistead et al. (1997) caution that a positive parent-child relationship is a better predictor of children's adjustment to the disclosure than the disclosure itself.

Disclosure is influenced by a variety of factors, including severity of physical symptoms (Armistead et al., 2001), deteriorating parental health (Lee and Rotheram-Borus, 2002), perceived stigma, mother-child relationship quality (Shaffer et al., 2001), and maternal concerns about talking about death and dying (Armistead et al., 2001). Mothers disclose more often than

fathers, and both parents tell their daughters more often than their sons (Armistead et al., 2001; Shaffer et al., 2001). Mothers reveal their HIV status to older children more than younger children (Armistead et al., 2001; Shaffer et al., 2001), but rates of disclosure do not vary by ethnicity. The two most frequently cited reasons HIV-infected mothers chose to disclose their status was "it was the right thing to do" and the need to make arrangements for parental custody planning (Pilowsky et al., 2000). Still, less than one third of mothers report disclosing their status to their children. Disclosure is often accompanied by a request that the teen "keep the secret," and the youth becomes the sole confidant for the parent (Murphy et al., 2002b; Reyland et al., 2002). Keeping the diagnosis a secret is related to greater adjustment problems (Kirshenbaum and Nevid, 2002). Thus, HIV-affected youths are caught in a "double-bind," wanting to protect their mothers yet also wanting support from family and friends (Murphy et al., 2002b; Reyland et al., 2002).

#### Child and Adolescent Mental Health and Behavioral Outcomes

Research findings are similarly inconclusive regarding children's adjustment to living with an infected family member. Some data suggest that affected and nonaffected youths do not differ on levels of psychopathology, self-esteem, substance abuse, or perceptions of parental bonding (Lee and Rotheram-Borus, 2002; Rotheram-Borus and Stein, 1999). Other evidence, however, indicates that affected children and adolescents display difficulties in all areas of functioning, including externalizing problems (e.g., aggression, disruptive behavior, attention problems), internalizing problems (e.g., withdrawal, depression, anxiety, somatic complaints), poor peer relationships, and cognitive deficits (e.g., academic performance, grades) (Biggar et al., 2000; Esposito et al., 1999; Forehand et al., 1998, 2002; Forsyth et al., 1996; Lee and Rotheram-Borus, 2002). In one study, children of parents living with HIV did not initially report high levels of emotional distress, but the impact of coping with HIV was associated with elevated rates of psychiatric disorders (39% anxiety disorders, 20% depression, 45% any disorder) (Lester et al., 2003; Rotheram-Borus et al., 2001a). Affected teens describe their own lives as "precious, short, and hard," and they worry about their mother's health,

potential or real social rejection, being labeled HIV positive, and the future (Brackis-Cott et al., 2003; Murphy et al., 2002b; Reyland et al., 2002).

Several mechanisms have been implicated in the relationship between parental HIV infection and child adjustment. Parental distress, children's increased role responsibilities (e.g., parentification), changes in family structure, reduced family income, perceived stigma, low social support, and planning for the future are some of the factors posited to potentiate negative child outcomes (Armistead and Forehand, 1995; Bauman et al., 2002; Dorsey et al., 1999; Forehand et al., 1998; Klein et al., 2000; Kotchick et al., 1997; Rotheram-Borus and Stein, 1999). Mental health problems and substance use among infected mothers are related to distress and increased risk of unprotected sex and drug use among daughters (Lee et al., 2002). Adolescent daughters are also at high risk of teenage parenthood to provide a grandchild to a dying parent (Rotheram-Borus et al., 2003). Chronic parental illness forces youths to assume a parental role in the household (Reyland et al., 2002) and responsibility for monitoring and maintaining the parent's health and emotional stability (Stein et al., 1999). Together with an ever-present fear of parental death, the childhood of these youths is typically shortened prematurely. The severity of maternal illness may also exacerbate negative child outcomes. Dorsey et al. (1999) found that mothers reported increased internalizing and externalizing problems in their children during symptomatic HIV but decreased mental health problems during the advanced stage of AIDS. Children in the same study, however, self-reported more symptoms as illness severity grew.

The most studied mechanism hypothesized to mediate children's adaptation to parental illness is parenting processes. HIV infection can disrupt parenting behaviors (Lee et al., 2002) and interfere with the parent-child relationship. For instance, infected mothers report less parental monitoring and poorer-quality mother-child relationships than noninfected mothers, and both of these parenting processes have been implicated in child maladjustment (Kotchick et al., 1997). Adolescent reports of low parental care have been linked to greater emotional distress, lower self-esteem, and elevated rates of conduct problems among daughters of infected mothers (Lee et al., 2002). Similarly, a positive parent-child relationship, strong parental monitoring outside the home, greater social support, and appropriate

routines inside the home are related to children's positive adaptation to maternal illness and fewer adjustment problems (Dutra et al., 2000; Forehand et al., 2002; Klein et al., 2000). Fathers can potentially buffer the negative effects of maternal infection, but affected children are more likely to have an infected father and to have less contact with their fathers than nonaffected youths (Pelton et al., 2001). All of these influences on children are compounded by numerous additional stressors common among women with HIV: poverty, victimization, discrimination, homelessness, violence, illness, and inadequate medical care.

## YOUTHS INFECTED WITH HIV/AIDS

### HIV/AIDS Definition

AIDS has been redefined during the past 20 years since HIV was identified as the causative agent and specific diagnostic tests were developed to identify the infection. The 1993 Centers for Disease Control and Prevention classification system defined AIDS according to CD4+ T-cell counts and clinical conditions associated with HIV infection including opportunistic infections (Centers for Disease Control and Prevention, 1993). Therefore, HIV-infected individuals with a CD4+ T-cell count of <200 were diagnosed with AIDS whether or not symptoms or other diseases were present. With the introduction of effective treatments in the mid-1990s, AIDS surveillance alone became inadequate to reflect trends in HIV transmission. Thus, in 1999, the Centers for Disease Control and Prevention revised the definition to incorporate laboratory criteria and recommended that reporting criteria for HIV and AIDS be combined into a single case definition (Centers for Disease Control and Prevention, 1999). The Centers for Disease Control and Prevention also urged states to require HIV surveillance, but this has not occurred nationwide. The most current definition was established for public health surveillance and not for clinical care. As a result, the age categories were recently revised from 0 to <13 years, 13–19 years, and 20–24 years to <13 years, 13–14 years, and 15–24 years. Thus, data about adolescents are often incomplete, overlapping, or extrapolated.

### HIV/AIDS Biology

HIV is transmitted through unprotected sex with an infected partner; through blood-to blood contact

as with shared needles; by infected mothers during pregnancy, delivery, or through breast milk; and, rarely, through untested blood products (more common in other countries). There are four recognized types of human retroviruses that belong to two distinct groups: the transforming human T-cell lymphotropic virus (HTLV) types I and II and cytopathic HIV-1, more common in the United States, and HIV-2. HIV-1 is further divided into groups, classes or subtypes, and circulating recombinant forms, all of which often indicate geographic origin (Fauci and Lane, 2001). The pathophysiology and pathogenesis known about this RNA virus are beyond the scope of this article.

Testing to diagnose HIV infection has evolved over time to provide quicker, more accurate, and cost-effective results. Until recently, all rapid HIV tests required blood samples, but in March 2004, the U.S. Federal Drug Administration approved a rapid diagnostic kit using saliva that provides screening results in as little as 20 minutes (U.S. Food and Drug Administration, 2004). Current testing approaches directly detect the virus or demonstrate antibody to the virus or a component, which usually appears 2–12 weeks after acute infection. These methods include enzyme-linked immunosorbent assay or enzyme immunoassay, Western blot, p24 antigen capture assay, HIV-1 DNA polymerase chain reaction, and HIV-1 RNA assay. A definitive diagnosis among infants younger than 15 months old cannot be made because their HIV-positive mothers may demonstrate HIV antibodies. Techniques to determine an accurate diagnosis between 3 and 15 months of age are being evaluated. HIV testing and counseling about HIV testing is critical, and guidelines are available (Centers for Disease Control and Prevention, 2001; <http://www.aidsinfo.nih.gov/>). Once diagnosed, the level of plasma HIV RNA (viral load) and the absolute numbers of peripheral CD4+ T cells are used to monitor clinical status. Advances in molecular methods and growing elucidation of HIV dynamics in vivo may make it possible to evaluate intracellular levels of different HIV RNA species and the amount of unintegrated and integrated HIV DNA (DeMilito et al., 2003).

### HIV/AIDS Sequelae

*Neurocognitive Deficits.* HIV is found primarily in microglia and macrophages and not directly in neurons. The virus is thought to have neurotoxic components

and to induce a variety of inflammatory factors that cause apoptosis, or programmed cell death, of neurons. Classification of the types of encephalopathy, static or progressive, is still unclear. Opportunistic CNS infections such as toxoplasmosis, progressive multifocal leukoencephalopathy, and CNS lymphoma are rare in pediatric AIDS and may present with seizures or focal neurologic signs (Mitchell, 2001). HIV encephalopathy is characterized by microcephaly or brain atrophy, motor abnormalities, and cognitive delays. Differential diagnosis includes possible intrauterine drug exposure to cocaine, alcohol, or other substances; opiate withdrawal; congenital infections with toxoplasmosis, syphilis, or cytomegalovirus; and *Cryptococcus* meningitis. In older children and adolescents, when cognitive development fails to progress appropriately, cerebral malformations, cortical dysplasias, hypoxic-ischemic encephalopathies, and progressive multifocal leukoencephalopathy should be considered.

The clinical presentation of HIV encephalopathy may vary with age of infection and mode of transmission. In children or adolescents infected through blood transfusion, encephalopathy generally presents later and follows a more indolent course. Encephalopathy is uncommonly an AIDS-defining illness for hemophiliacs. By contrast, in as many as 21% of vertically HIV-infected children, encephalopathy can present and contribute significant morbidity and mortality as an AIDS-defining illness even when the child is not severely immunocompromised (Cooper et al., 1998; Tardieu et al., 2000). Early progressive encephalopathy is usually seen in young untreated infants with high viral loads and rapid clinical deterioration. Additional risk factors for children developing early progressive encephalopathy are advanced maternal HIV disease, maternal encephalopathy, and possibly co-infection with cytomegalovirus. Expressive language is affected more severely than receptive language in children with vertically transmitted HIV (Wolters et al., 1995). In the Women and Infant Transmission Study Group study, scores on the Bayley Scales of Infant Development independently predicted mortality even after adjusting for age, viral load, CD4 counts, and treatment (Llorente et al., 2003).

Neuroimaging of microcalcifications on computed tomography can detect abnormalities, but findings lag behind clinical encephalopathy. The most common computed tomographic findings associated with encephalopathy are basal ganglia calcifications, brain atro-

phy with enlarged ventricles, and enlarged cortical sulci (Belman et al., 1986; Brouwers et al., 1994). Magnetic resonance imaging (MRI) may detect mass lesions found in toxoplasmosis or CNS lymphoma. MRI is also useful in detecting cerebrovascular complications because HIV-infected children have a higher incidence of ischemic strokes and cerebral artery aneurysms that may expand or rupture (Civitello, 2003). MRI screening has been recommended for high-risk children who are asymptomatic from HIV disease but are displaying neurocognitive dysfunction (Patsalides et al., 2002). A positron emission tomography study revealed diffuse hypometabolism in some children with severe encephalopathy (Depas et al., 1995), but positron emission tomography and functional MRI remain largely theoretical tools for early detection of neurocognitive deficits at this time.

Practitioners are finding more adolescents with late stage AIDS who show gradual progression into dementia with bradykinesias, spasticity, and hallucinations regardless of the mode of transmission. Adolescent patients who are long-term survivors may have cognitive problems, particularly in memory and attention. The continuous performance test may be useful to detect subtle changes in attention (Watkins et al., 2000). As HIV-infected youths live longer, cognitive issues are emerging and their educational needs are significant (Armstrong et al., 1993; Cohen et al., 1997).

*Psychiatric Illness.* The presence of HIV may cause CNS compromise, but how HIV infection affects the developing brain from infancy through adolescence is largely unknown. Psychiatric symptoms are thought to be in part the result of direct infection of the CNS with HIV but also in part of comorbid medical complications of HIV such as opportunistic infections, neoplasms, and cerebrovascular disease. Other prenatal insults from substance abuse, genetic predisposition to psychiatric conditions, poor nutrition, and environmental circumstances may be significant contributing factors.

Psychiatric disorders in children with HIV/AIDS seem to vary by the mechanism of viral transmission, which, in turn, is influenced by factors such as age and viral load at time of infection, HIV treatment availability and duration, rate of cognitive deterioration, and other biological and psychosocial factors reviewed elsewhere (Brown and Lourie, 2000; Lwin and Melvin, 2001). Among infants and children vertically infected with HIV, neurological and neuropsychological deficits have

been carefully examined over time, although few studies report formal psychiatric diagnoses. Data suggest rates of depression, anxiety, behavioral, and social problems ranging from 12% to 44% in this population (Mellins et al., 2003). One early study of psychiatric morbidity in 5- to 12-year-olds compared 26 perinatally infected children prenatally exposed to maternal drug abuse with 14 seroreverted children (prenatally HIV exposed) and 20 HIV-negative children exposed to maternal drug abuse. Caregivers reported attention-deficit/hyperactivity disorder (21%) as the most common psychiatric diagnosis among perinatally infected youths. Rates were also high in the control groups, suggesting that genetics and prenatal alcohol and tobacco exposure may be more important influences on the development of ADHD than HIV per se. The HIV-positive children and their parents also reported more symptoms of anxiety than controls (Havens et al., 1994). The Women and Infant Transmission Study Group study compared HIV-infected children with uninfected siblings born to HIV-positive mothers. Findings confirmed earlier data revealing high rates of hyperactivity and impulsivity in both the infected and uninfected children. Mellins et al. (2003) suggest that behavioral problems in these youths may not result from HIV or prenatal drug exposure but rather from other biological and environmental factors such as poverty. Recent data by the Pediatric AIDS Clinical Trials Group found a higher frequency of psychiatric hospitalization among perinatally infected children compared with the general pediatric population and HIV-uninfected members of the cohort (Gaughan et al., 2004). Finally, a small study of HIV-infected adolescents who acquired HIV as adolescents revealed a substantial history of psychiatric disorders including substance abuse, whereas 44% qualified for depression at least 6 months after the HIV diagnosis (Pao et al., 2001).

Little is known about mental health problems among children infected through blood transfusions. One study of children with hemophilia indicated that youths with HIV reported higher rates of anxiety disorders than children without HIV or children with asthma (Bussing and Burket, 1993). There are no data regarding how psychiatric symptoms and disorders affect survival rate in youths. Blossoming areas of research include the roles of cytokines; cortisol, a marker in the hypothalamic-pituitary-adrenal axis; and autonomic nervous system transmitters such as

norepinephrine on immune function and therefore on disease progression.

#### HIV/AIDS Disclosure

Complex issues concerning when to disclose remain unclear, as knowledge of one's HIV status is associated with both more and less emotional distress and depression (Battles and Wiener, 2002; Fanos and Wiener, 1994; Gaughan et al., 2004; Lester et al., 2002; New et al., 2003). The level of distress depends on how the disclosure occurs, under what circumstances, and the reaction of the other person. Telling a child that he or she has HIV appears to be influenced by several factors, including older child age, higher child intelligence, recent major life event, and higher family expressiveness (Lester et al., 2002). Still, 25% to 90% of HIV-infected school-age children have not been told their diagnosis (Funk-Brentano et al., 1997; Grubman et al., 1995; Wiener et al., 1996). Current pediatric practice guidelines encourage disclosure by adolescence (American Academy of Pediatrics, 1999), but neurocognitive deterioration may complicate the timing. Gerson et al. (2001) recently reviewed how medical teams can facilitate the process of disclosure, but parents do not always agree with the recommendations. Nevertheless, public health concerns have led some states to consider mandating medical teams to disclose HIV serostatus to youths before they become sexually active. Simply telling teens that they are HIV positive may not reduce risky sexual behavior, however. In fact, few teens disclose their status to sexual partners. Among HIV-positive males with hemophilia, 58% did not disclose their HIV status to their most recent sexual partner and there was no correlation between disclosure and condom use (Geary et al., 1996). These findings underscore the importance of emphasizing safer sex practices for all teens regardless of HIV status.

#### HIV/AIDS PREVENTION

Although significant progress has transformed AIDS into a chronic medical illness, there is still no cure and behavioral prevention remains the most viable strategy to reduce the spread of infection. The types of prevention programs and settings in which they are delivered have evolved during the past 10 years in response to greater recognition of the diverse needs of the populations being served. Programs vary in their emphases; many stress abstinence until marriage, whereas others

promote abstinence and also discuss condom use and other contraceptives. Carefully constructed, culturally relevant sexual and substance use behavior change interventions can and do reduce HIV transmission acts (Peterson and DiClemente, 2000), but not all programs are equally effective.

#### Abstinence-Only Education

There are only a few empirical reports of abstinence-only and abstinence until marriage programs (Thomas, 2000), but available research has failed to find a reduction in sexual behavior, especially for sexually experienced youths (Bearman and Brueckner, 2001; Jemmott et al., 1998; Kirby and Coyle, 1997).

#### Comprehensive Sex Education

There is considerable evidence that comprehensive sexuality and HIV education programs have led to later sexual debut, less frequent sexual activity, fewer partners (Kirby, 2002a), decreased likelihood of unprotected sexual intercourse at the time of first sex (Kirby, 2001; Low-Beer and Stoneburger, 2001; Rosenfeld et al., 2001), and reduced risk taking among HIV-positive youths (Rotheram-Borus et al., 2001b). These programs encourage abstinence, discuss correct condom use, educate teens about early identification and treatment for STDs, and teach sexual communication skills (e.g., how to refuse sexual activity, discuss condom use, and assert one's values and opinions). Despite recent claims, there is no evidence that these programs hasten sexual debut or increase intercourse frequency (Blake, 2003; Office of the Surgeon General, 2001), but they are effective at reducing sexual risk taking among sexually experienced adolescents (Mullen et al., 2002).

#### HIV-Risk Reduction Programs

Early HIV prevention programs were designed to increase AIDS knowledge, change attitudes and beliefs, enhance motivation to prevent HIV, and increase behavioral intentions to reduce risk (DiClemente et al., 1996). These efforts yielded positive results; teens reported greater AIDS knowledge, more realistic beliefs about susceptibility, positive perceptions of risk reduction, and greater feelings of self-efficacy to prevent HIV. Unfortunately, changes in health-risk behavior (e.g., noncondom use) were minimal. The limited effects

may be explained, in part, by (1) the lack of sensitivity to adolescent development in curriculum design, (2) minimal attention to contextual factors associated with HIV risk, and (3) the omission of factors specific to teens' risk taking.

The second generation of prevention efforts responded to these limitations by emphasizing behavior change strategies and by making practical suggestions for teens in real-life situations. Most of the programs include school-based or general population youths (Kirby, 2002b; Kirby and Coyle, 1997) and emphasize developmental and motivational aspects of adolescent risk taking. These programs encourage abstinence and delaying sex as well as reducing the frequency of sexual activity. Youths learn skills such as how to use a condom and improve sexual communication with partners. These programs have led to important risk reduction behaviors, including less sexual activity, fewer partners, increased condom use, later sexual debut, positive attitudes about prevention, greater behavioral skills to negotiate safer sex and resist peer pressure to engage in risky behavior, and improved parent-teen communication about abstinence and contraception. It is unclear whether the short-term effects were maintained, as most studies did not examine effectiveness beyond 12 months. However, one-shot quick-fix approaches appear to be less effective than longer, more intensive interventions (Rotheram-Borus et al., 1998).

#### HIV/AIDS Prevention for Teens in Psychiatric Care

Few programs have been designed specifically for teens with mental health problems, but efforts to customize HIV prevention interventions for adults with psychiatric illness are promising. Innovations include redundant and concrete presentations of material, personalized risk "triggers" (e.g., substance use and feelings of hopelessness), emphasis of affect regulation, and discussion of the benefits, costs, and barriers to change (Kelly, 1997; Otto-Salaj et al., 1998). Some HIV prevention programs for mentally ill adults have been integrated into community-based mental health clinics (Otto-Salaj et al., 1998).

Additional adaptations may be needed for youths in psychiatric care. For instance, teens may benefit from family member involvement, improving parent-teen communication about sexual topics, and coping with negative emotional arousal in sexual situations. Only two published

papers report the effects of HIV prevention interventions for teens in psychiatric care. Brown et al. (1997c) sought to increase knowledge and personal concern about HIV/AIDS and to enhance perceptions of self-efficacy to prevent transmission. Cognitive distortions associated with risky behavior were addressed using role-playing and other strategies. Immediately following the intervention, youths reported increased AIDS knowledge, greater tolerance of people with AIDS, more safe-sex intentions and self-efficacy, and greater anxiety about getting HIV; however, the effects did not last. In a second study, Ponton et al. (1991) used several strategies (e.g., worksheets, discussions, a visit from someone with AIDS, essay writing on an AIDS-related topic, role-playing, exploring decision making, and hands-on practice applying condoms) to increase healthy behavior. Adolescents reported no change in perceived risk of infection or AIDS knowledge, but misconceptions about casual contact and intentions to engage in risk behavior (e.g., not using condoms) decreased. There was no long-term follow-up. Together, these findings suggest modest effects of HIV prevention efforts targeting severely mentally ill youths.

Recent HIV prevention programs are incorporating important contextual factors that influence adolescents' risky behavior, such as families and communities (Pequegnat and Szapocznik, 2000). Two ongoing multisite, randomized, controlled trials are under way to address the unique needs of youths in psychiatric care. One program is designed to strengthen the parent-adolescent relationship and increase parent-teen communication about sexual topics to reduce risk. The other study is teaching teens attending therapeutic day schools to manage their negative emotional arousal to prevent unsafe behavior. Findings from both projects will yield important information about the critical components that reduce high-risk behavior in this population.

## HIV/AIDS TREATMENT

### Biological Approaches

Identification of the replication cycle and genome of HIV has led to the development of numerous treatment strategies. Treatments are constantly evolving in response to the changing biology of the virus, making HIV vaccine development difficult (Gaschen et al., 2002). The treatment regimens for people with HIV/AIDS are now so complex that toxicity, adherence, and viral resistance

are just some of the issues that make following antiretroviral regimens difficult for youths. Information is regularly published and updated at <http://www.aidsinfo.nih.gov/guidelines/> regarding therapy for children and adolescents (Centers for Disease Control and Prevention, 1998b; Dybul et al., 2002).

Four main classes of antiretroviral medications are available to treat HIV: (1) nucleoside analogue reverse transcriptase inhibitors (NRTIs), (2) non-NRTIs, (3) protease inhibitors, and (4) fusion inhibitors, a new class currently under investigation. Highly active antiretroviral therapy refers to the use of multiple drugs of different classes in combination with a protease inhibitor. Non-NRTIs and protease inhibitors are inhibitors of cytochrome P-450 enzymes. Most HIV medications are P-450 substrates changed by the specific enzyme 3A4. HIV protease inhibitors are all cytochrome P-450 3A4 enzyme inhibitors. Thus, drug interactions with psychotropic medications are a serious concern and must be closely monitored. Even herbals and foods like St. John's wort, grapefruit juice, and brussels sprouts are examples of inducers of P-450. Researchers have shown that grapefruit juice significantly reduces indinavir concentrations (Piscitelli and Struble, 2001). A useful cytochrome P-450 drug interaction table is maintained at <http://medicine.iupui.edu/flockhart>. Some antiretroviral drugs have been reported to cause psychiatric symptoms among HIV-positive youths, including mania with zidovudine and attention-deficit problems with efavirenz (American Medical Association, 2004), although no systematic study has been done.

*Encephalopathy.* Encephalopathy frequently develops with HIV disease progression. Cognitive testing and imaging studies have yielded promising evidence that antiretroviral medications, particularly those agents with CNS activity, reverse encephalopathy. Complete adherence is paramount to achieve these benefits (Brouwers et al., 1990; McCoig et al., 2002; Tepper et al., 1998). In children, combination therapy with zidovudine (previously called AZT) and didanosine appears to be more effective against CNS manifestations of HIV disease such as neurologic deterioration, impaired brain growth, and declines in neurocognitive testing than either of the monotherapies (Raskino et al., 1999). Adverse effects of NRTIs have been reported to contribute to progressive encephalopathy, peripheral neuropathy, and myopathy via depletion of mitochondria and subsequent lactic acidosis (Church et al., 2001). Reports suggest that NRTIs may

cause mitochondrial damage via in utero exposure, but this has not been substantiated by follow-up investigations. A recent study indicated that when a change in cognitive function is noted even when peripheral markers are stable, switching antiretroviral medications to include those with better blood-brain barrier penetration may be warranted (Tamula et al., 2003).

*Psychiatric Symptoms.* Psychiatric management of children and adolescents with HIV/AIDS remains largely empirical. Two primary classes of medications, antidepressants and stimulants, have been used to treat psychiatric disorders such as mood, anxiety, and attention disorders as well as symptoms of insomnia and amotivation in HIV-positive youths (Donenberg and Pao, 2004). There are no data to support greater effectiveness of one antidepressant over another for depression in infected children and adolescents. A depressed adolescent with hemophilia and AIDS was successfully treated for depression with methylphenidate. The same case report describes how stimulants may potentiate opiate treatments that may be clinically relevant in the treatment of pain syndromes and depression in late HIV/AIDS (Walling and Pfefferbaum, 1990). Psychostimulants may be an alternative treatment for youths who cannot tolerate antidepressants for mood or pain symptoms. Psychostimulants are frequently used to treat attention-deficit/hyperactivity disorder in children with HIV, and clinical trials are under way to determine appropriate doses for children receiving antiretrovirals. A case report also suggests clonidine was well tolerated by young children with HIV to treat behavioral problems (Cesena et al., 1995).

*Medication Adherence.* Nonadherence to medical regimens is common among children and adolescents with a chronic illness. Unfortunately, in HIV disease, intermittent or minimal nonadherence can lead to viral replication, mutation, and subsequent development of drug resistance, which will have significant clinical impact and limit future treatment options. Reported adherence rates in HIV-positive youths range from 28% to 90% (Murphy et al., 2003; Steele and Grauer, 2003). Adherence can be measured in a variety of ways (e.g., counting prescriptions filled, parental report, electronic monitoring, drug level monitoring) (Dolezal et al., 2003; Watson and Farley, 1999). High levels of adherence are associated with improved virologic response (Gibb et al., 2003; Van Dyke et al., 2002). Multiple factors influence adherence among youths, such as child

age, regimen complexity, drug palatability, symptomatic HIV disease, family beliefs, and caregiver's mental health, to name just a few (Wiener et al., 2004). Adherence strategies depend heavily on family or social support and disclosure status (Dodds et al., 2003). Novel approaches that include family and peer groups to improve adherence have been piloted (Lyon et al., 2003). Simoni et al. (2002) provide a review of funded interventions enhancing combination antiretroviral adherence in adults and youths.

#### Behavioral Approaches

*Infected Youths.* Individual, family, and group interventions are an important adjunct to successful treatment of HIV-infected and -affected youths. For infected teens, prevention programs emphasize reducing transmission acts, enhancing quality of life, increasing self-care behaviors, improving medical adherence, coping with medication side effects, appropriate disclosure (e.g., to whom, when), and interactions with health care providers (Rotheram-Borus and Miller, 1998). Rotheram-Borus et al. (2001b) have tested a number of preventive interventions for youths living with HIV using therapeutic approaches based on cognitive behavioral principles. One intervention included two primary components: (1) increasing positive health behaviors, particularly around medication adherence, and (2) enhancing altruistic motivations to reduce transmission acts. The intervention emphasized coping with being HIV positive, adopting healthy routines, partaking in health care decisions, reducing substance use and risky sexual behavior by identifying risk triggers, and increasing self-efficacy to use condoms and negotiate safe sex. The intervention sought to build skills and improve emotion regulation—similar strategies used to enhance psychological functioning for youths in psychiatric care. Teens who received the intervention reported more lifestyle changes, improved coping, fewer sexual partners, and a lower percentage of unprotected sexual acts than youths who did not receive the intervention. Additional sessions emphasized increasing life satisfaction and emotional strength (Rotheram-Borus et al., 2001c). The additional sessions reduced emotional distress and psychiatric symptoms among the infected youths, including somatization and anxiety.

Programs have also been developed to help the adult caregivers of youths with HIV. These programs teach effective parenting skills, parental monitoring of medication adherence, and increasing social support among

family members and the community (Lyon et al., 2003). Some of the more innovative interventions also address the caregivers' mental health and quality of life.

*Affected Youths.* Few services are available to assist children and adolescents of HIV-infected family members despite potential long-term intergenerational consequences of HIV illness. The few programs with published data have yielded positive effects for affected teens. These programs address coping with stigma and illness-related tasks, parental disclosure, increasing maternal well-being and social support, effective parenting skills, decreasing victimization, custody planning, maintaining positive family routines, and emotional reactions to AIDS (Rotheram-Borus et al., 2001a). Two- and 4-year follow-up studies of intervention effects have been both promising and disappointing. Two years after the intervention, teens reported significantly fewer conduct problems, less emotional distress, lower levels of family-related stress, and higher self-esteem than teens in a control condition. Outcomes were comparable for youths who were bereaved and nonbereaved by parental AIDS and across ethnic and gender subgroups (Rotheram-Borus et al., 2001d). Unfortunately, the positive effects eroded by the 4-year follow-up, underscoring the need for sustained support and treatment for these families (Rotheram-Borus et al., 2003).

HIV prevention programs for affected youths must address intergenerational imitation of HIV risk behaviors, substance abuse, and mental health disorders and help young people cope with HIV-related psychosocial challenges (e.g., bereavement). Although often neglected or overlooked, there is an important role for religion or spirituality as sources of support and strength for families affected by HIV/AIDS (Ironson et al., 2002; Pargament et al., 2004; Simoni et al., 2002). Unfortunately, psychosocial interventions have not been broadly implemented or prioritized to date, particularly within the medical settings that care for infected persons. Thus, affected family members receive few if any services. To reduce the negative intergenerational impact of HIV, these interventions must be viewed as cost-effective, acceptable to providers and consumers, and easily accessible to the population (Borus et al., 2004).

## CLINICAL IMPLICATIONS

Ongoing research to uncover the underlying risk mechanisms associated with HIV/AIDS risk is essential

to understanding and curbing the AIDS epidemic. The most successful HIV prevention and intervention strategies are not new to mental health practitioners; they have simply not been used in this context. Most clinicians regard HIV/AIDS as a public health and not a psychiatric issue, and, thus, teenage sexual activity has been considered outside the realm of psychotherapy. Yet, HIV/AIDS has significant mental health implications, and HIV prevention programs are more effective when they include a mental health component (Stiffman et al., 1992). One-on-one patient-provider discussions in health settings have led to reduced adolescent sexual risk behavior and drug use (Kirby, 2002a); thus, psychiatry, too, can play a critical role in stemming the tide of new infections.

Mental health professionals are in a unique position to influence sexual behavior and drug use among youths in psychiatric care and to assist families affected by HIV disease. Successful risk-reduction strategies can be incorporated into traditional clinical settings, and commonly used approaches to treat psychiatric disorders can be readily adapted and applied to HIV prevention and intervention. One-to-one with youths, clinicians can provide accurate information about risks of transmission and strategies for protection, help teens understand the behaviors that lead to HIV/STD infection, and identify and avoid external and internal triggers for high-risk behavior. Mental health practitioners can employ a variety of strategies to personalize information to enhance motivation for prevention (e.g., videos, role-plays, coaching). Reframing and challenging negative thoughts and beliefs about practicing safe sex are a natural extension of cognitive-behavioral therapy principles. Addressing social pressures, developing behavioral goals, and rehearsing sexual communication and refusal skills are easily applied in a clinical setting. As with traditional psychotherapy, clinicians can help youths develop coping strategies to regulate negative emotional arousal to reduce the likelihood of risky sex, weigh the costs and benefits of short-term relief gained by sexual risk taking, and practice assertive communication with peers and romantic partners. Working with families, mental health practitioners have an unparalleled opportunity to help parents reduce teenage risk by teaching them to monitor and supervise their adolescents, communicate effectively (especially about sexual topics), and model healthy behavior. Clinicians can address appropriate role responsibilities for youths

and issues related to HIV disclosure (e.g., to whom, where, when). Support for families infected with and affected by HIV/AIDS must be ongoing and consistent. Mental health providers are in a perfect position to provide this needed sustained support.

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