The HIV/AIDS epidemic is a growing health crisis among women in the United States. In the early stages of the epidemic, relatively few women and female adolescents were diagnosed with HIV infection and AIDS. Today, women, especially those of color, represent an increasing proportion of new diagnoses and deaths.

The Centers for Disease Control and Prevention’s (CDC) HIV/AIDS surveillance system collects reports of cases of HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immunodeficiency Syndrome) as they are diagnosed. HIV/AIDS Surveillance is a uniform system in which the CDC receives reports of AIDS cases from all U.S. states and territories. According to these data, more than a million adults and adolescents (>13) are living with HIV/AIDS; of these, 24% are women (CDC, 2012).

In 2010, HIV infected an estimated 9,868 women in the United States\(^1\), down from 11,329 in 2007 (CDC, 2012). However, an increasing number of women are living with HIV/AIDS – a change resulting primarily from the widespread use of highly active antiretroviral therapy (HAART), introduced in 1996, which has delayed the progression of AIDS to death (CDC, 2007b). Between 1998 and 2009, the population of women living with AIDS shot up 90%, from approximately 57,300 to about 110,945 (CDC, 2002; 2012). In addition, while AIDS was the third leading cause of death in 1995 among women 25 to 44 years old, (National Center for Injury Prevention and Control [NCIPC], 2007), it dropped to the sixth leading cause of death in 2007 for this demographic (NCIPC, 2009). Nevertheless, infected women are at greater risk of HIV/AIDS-related morbidity and mortality than men (Meditz et al., 2011).

These data, however, provide an incomplete picture of the HIV epidemic. For example, they do not capture cases not reported to the CDC, such as those in which the HIV testing was conducted through anonymous means or through the use of home-based test kits. They also do not capture the estimated 73% of all women who have not been tested and, as a result, do not know their HIV status (CDC, 2007b; “MAC AIDS Fund Survey”, 2010).

Impact on African American and Latina Women

Women of color, especially African Americans and Latinas, are disproportionately affected by this epidemic. Although African Americans and Latinas combined comprise about 27% of all women in the United States, they account for an estimated 81% of new AIDS diagnoses among women (CDC, 2012;\(^1\)

---

\(^1\) These statistics come from 46 states with confidential name-based HIV infection reporting.
U.S. Census Bureau, 2011). Moreover, the number of AIDS cases is higher among African American women than all other racial/ethnic groups combined (CDC, 2012). Although rates among Latinas are lower than the rates among African American women, the Latina population also contracts the disease at a disproportionately higher rate than Whites. Unfortunately, many minority women do not receive needed treatment. RAND’s (2000) HIV Cost and Services Utilization Study found that HIV-infected African Americans and Latinas were less likely to receive preventative treatments and outpatient care than Whites. Furthermore, nonwhites show greater HIV/AIDS-related morbidity and mortality in relation to Whites (Meditz et al., 2011).

TRANSMISSION OF HIV TO WOMEN

The most frequent routes of HIV infection in women have shifted since the beginning of the epidemic. In the 1990’s, most women were infected through intravenous drug use. Currently, most women are infected during sexual intercourse with an HIV-infected man. In 2010, an estimated 86% of women diagnosed with HIV were exposed through heterosexual contact, up from 28% of cases in 2001 (CDC, 2002; 2012). In contrast, only 14% of HIV diagnoses among women in 2010 were due to injection drug use (CDC, 2012).

MOTHER TO CHILD TRANSMISSION

With medical advances, women with HIV are living longer and healthier lives, and many of them are having children (Finocchiaro-Kessler et al., 2009). While a child can be a positive addition to a woman’s life, there is a risk that an HIV-infected pregnant woman will pass on the virus to her child. In fact, mother-to-child transmission (MTCT) is the primary method by which the disease infects children under 13 (CDC, 2012), and it can occur at any one of three stages: during pregnancy; during labor and delivery; or after birth, via breastfeeding. Transmission during labor and delivery is the most common means of infection (Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission [PTHPW], 2011). Without treatment, transmission of HIV occurs in 20-45% of pregnancies.

However, mother-to-child transmission is now avoidable. Transmission rates are reduced to less than 2% when the following precautions are taken: HAART, during pregnancy; intravenous administration of the drug AZT during labor and delivery; cesarean delivery when appropriate; AZT administered to the newborn for 6 weeks after birth; and avoidance of breastfeeding (CDC, 2006b). Since HAART therapy was introduced in the early 1990s, the number of new perinatally transmitted HIV cases has decreased by about 90% (CDC, 2006a). Combination therapy for HIV has become the standard, with the large majority of the women (86%) taking more than one HAART drug during the third trimester of pregnancy (Shapiro et al., 2002).

While research has demonstrated the reduced risk and incidence of MTCT, certain barriers remain. Cooper et al. (2002) found that infected women who did not receive HIV treatment during pregnancy had certain salient characteristics. Many of these women were under 30 years of age, were unaware
of their HIV status, and had used drugs during pregnancy. Furthermore, many women do not realize that treatment is available to help prevent MTCT (CDC, 2007c).

**CHILDREN WITH HIV/AIDS**

As in the adult population, the number of pediatric HIV/AIDS cases is declining. The number of new AIDS diagnoses among children declined from about 950 in 1992 to only 23 in 2010 (CDC, 2012). In addition, the number of children dying from AIDS has dropped in recent years: an estimated 46 AIDS-related deaths were reported among children in 2009, compared to 107 in 1999 (CDC, 2002, 2012). Because nearly all HIV-infected children contract the disease through perinatal transmission, HIV/AIDS in children closely resembles that of women. That is, African American and Latino children are over-represented among infected children. In 2010, they accounted for 81% of pediatric (<13) HIV diagnoses (CDC, 2012).

**HIV/AIDS SYMPTOMS AND OUTCOMES**

HIV works to impair the human immune system, making people vulnerable to numerous life-threatening infections (CDC, 2010a). Without treatment, HIV is almost universally fatal. HIV can have unique medical indications in women. For example, women with HIV often experience severe pelvic inflammatory disease; HPV infections; and persistent, frequent vaginal yeast infections (HIV InfoSource, 2009). In addition, they tend to have higher rates of herpes simplex infections compared to the general population. Herpes can also make a person more susceptible to HIV and can make HIV-infected persons more infectious (CDC, 2010b). Women with HIV are also at greater risk for certain cancers, especially cervical cancer, which is primarily caused by HPV (Kalra, 2010). Women with HIV who develop cervical cancer have poorer immune system status and do not respond as well to antiretroviral therapy as HIV-infected women without cancer.

Infants and children with HIV exhibit their own constellation of medical symptoms and problems (Davies, Bachanas, & McDaniel, 2002). For example, if not treated with HAART, they can suffer from weight loss; slowed growth; damage to the brain and central nervous system; and heart, liver, or skin problems. Like infected adults with damaged immune systems, children with HIV are much more susceptible to other ailments, including frequent bacterial infections, ear or sinus infections, and recurrent thrush (a yeast infection in the mouth). HAART typically reduces or eliminates these health problems.

**HIV TESTING**

To detect HIV early, the CDC recommends offering HIV screening for patients in all healthcare settings, and encourages people at-risk for infection to be screened at least annually (CDC, 2006b). They advocate making voluntary HIV testing a routine part of medical care, much like screenings offered for other treatable conditions. The screening tests available are reliable, inexpensive, and non-invasive, and allow physicians to begin interventions before symptoms develop and help prevent the
disease from spreading. The shift from testing only high-risk individuals to routine testing is an attempt by the CDC to reach the estimated 21% of Americans who are already infected with HIV, but are unaware of their status (CDC, 2009b). Universal, routine testing also has the advantage of reducing the stigma associated with assessing high-risk behaviors. In contrast, targeted testing often fails to capture large numbers of infected persons who do not seem at-risk or are unwilling to discuss their risky behaviors.

Universal HIV screening of women is the ultimate goal, but there are differences in how states approach testing. Some states use an opt-in approach, which requires that patients specifically consent to HIV testing. Several notable barriers limit the effectiveness of this approach. For instance, some physicians may not encourage testing strongly enough (Association of Maternal & Child Health Programs [AMCHP], 2006). Even with physicians’ urging, women may not opt for testing because they don’t believe they are at risk or they fear the consequences of a positive test result. With uneven opt-in testing practices, many cases of HIV may continue to be missed.

The opt-out approach, on the other hand, notifies patients that an optional HIV test will be automatically included in a standard battery of tests and procedures (CDC, 2006b). This method yields higher testing rates and has been shown to be more cost effective than risk assessment or opt-in approaches (Immergluck, Cull, Schwartz, & Elstein, 2000). However, the opt-out approach has yet to be implemented in many medical care settings.

In addition to implementing universal HIV testing in medical clinics, researchers suggest that efforts must be directed towards screening at-risk women in a variety of settings outside of physicians’ offices. According to a study by RAND (2005), the primary barrier preventing a woman from getting testing for HIV was the belief that she was not at risk. Women with these beliefs, along with those without regular health care might be screened and tested in alternative settings.

The U.S. Department of Health and Human Services (DHHS; 2012) advocates a “test and treat” approach to preventing the spread of HIV/AIDS. It is a two-pronged method involving 1) regular HIV testing of all adults and 2) HAART, patient education, and supportive services for all infected persons, regardless of immune system status. It addresses the concern that many Americans with HIV are unaware of their status and capitalizes on the fact that early treatment prevents mortality and HIV transmission. Nevertheless, barriers to its implementation remain, such as providing adequate resources for HIV/AIDS care (the cost of which has increased), testing high-risk persons (who are often hard to reach), and maintaining people in care. The U.S. DHHS asserts that some of these challenges will be removed and test and treat’s potential for success improved once the Patient and Affordable Care Act is fully implemented.

**Testing among Pregnant Women and Infants**

HIV testing is particularly important among pregnant women and infants. A primary strategy to prevent perinatal transmission is to maximize prenatal HIV testing of pregnant women and include voluntary testing as a routine component of both preconception and prenatal care (CDC, 2009b). In the past, medical providers screened and tested only women who were considered “at-risk” for HIV,
thereby failing to diagnose women without established risk factors (AMCHP, 2006). To remedy this, the CDC (2006b) now recommends that all pregnant women in the U.S. be screened for HIV infection using the opt-out approach. The CDC also recommends additional screening in the third trimester in regions with elevated rates of HIV infection. Initiation of appropriate antiretroviral treatment is recommended to women upon positive HIV test results (PTHPW, 2011).

The CDC also recommends that newborns be tested for HIV, with or without the mother’s consent, if the mother has HIV or if her status is unknown at delivery (CDC, 2007d). Because newborns receive maternal antibodies to protect them while developing their own immune systems, the HIV antibody tests most commonly used to diagnose HIV are not accurate in newborns. Therefore, the standard of care for newborns entails direct testing for the HIV virus at two weeks, four weeks, and four months. If the tests at two and four weeks are negative, then the child is presumed to be uninfected. If the test at four months is also negative, the child is considered definitively not infected. Many clinics will also do an antibody test on the child after 1 year of age, to be certain that the maternal HIV antibodies have cleared (PTHPW, 2011).

Rapid HIV Tests

Historically, a significant barrier preventing routine HIV testing during pregnancy and labor and delivery has been the length of time it takes to get testing results (CDC, 2007a). However, four rapid HIV tests have been approved for use by the Food and Drug Administration (FDA), and are now commercially available in the U.S.

An accurate rapid test has several potential applications in prenatal and labor and delivery settings to prevent prenatal transmission. Immediate knowledge of the mother’s HIV status provides an opportunity for starting HAART therapy and utilizing other interventions, such as elective cesarean section and avoidance of breastfeeding, to reduce transmission (CDC, 2007d). Additionally, a rapid test can be valuable for those women who are unlikely to return for test results.

PSYCHOSOCIAL FACTORS

Fully understanding the challenges faced by persons with HIV/AIDS involves recognizing the strong link between psychosocial issues and behaviors that lead to HIV infection, including unsafe sex and illicit drug use. It is sometimes difficult to determine which factors pre-date the illness and which are a consequence of it, but addressing associated issues may aid prevention and intervention efforts.

Poverty

Economic and employment problems form one family of issues associated with HIV/AIDS among women. Heterosexual individuals living below the poverty line in U.S. cities are five times as likely as the general population to be HIV-positive (CDC, 2010c). This may be the result of unemployment, low

---

2 According to the data from publicly funded counseling, about 30% of persons who test HIV-positive and 39% of persons who test HIV-negative do not return for their results (CDC, 2007b).
education levels, lack of private health insurance, and high rates of substance abuse among low-income populations, all of which limit health care access (HIV/AIDS Bureau, 2004). In addition to lacking needed health care, many poor HIV-infected women are exposed to high levels of violence and experience poorer quality of life than those who are more affluent (Murphy, 2009). Contracting HIV/AIDS also places an enormous financial burden on the infected patient. Those with HIV/AIDS may be unable to continue working while facing exorbitant health care costs. Women are disproportionately impacted by the financial burdens of HIV/AIDS, as they tend to be poorer than males infected with HIV. About 64% of HIV-infected women, but only 41% of men with HIV, have annual incomes below $10,000 (Bozzette et al., 1998). In part because they tend to live with HIV-infected mothers, children with HIV are also more likely than healthy children to live in poverty.

**Violence and Abuse**

In addition to being impoverished, many women with HIV/AIDS have experienced violence and abuse. Childhood physical and sexual abuse are linked to high-risk sexual behaviors among women, including early sexual initiation, sex with unfamiliar partners, and low rates of condom use. All of these put women at risk for HIV (Wyatt et al., 2003). This is partly because childhood abuse victims often develop poor physical, mental, and sexual self-images, which may cause them to feel powerless and insecure in their adult relationships. Consequently, they may seek comfort or attention even if it entails sexual relations with multiple partners or other forms of high-risk sexual activity. Some women find intimacy in their relationship to be more important than protection against HIV (Center for AIDS Prevention Studies, 2008).

Although rates of intimate partner violence (IPV) among HIV-infected women are similar to rates among HIV-negative women, Gielen and colleagues (2007) suggest that the abuse HIV-infected women receive is more frequent and severe. They also note that the demographics of women experiencing high rates of IPV are often similar to those of women who are at high risk for HIV infection (e.g., women in poverty, young women, and those who use illegal substances). IPV also may interfere with a woman’s ability to protect herself against HIV or may contribute to other risky behaviors. For instance, posttraumatic stress disorder resulting from partner violence is strongly correlated with high-risk sexual behavior, including having unprotected sex with a partner who is an injection drug user or who is known to be HIV-positive (Cavanaugh, Hansen, & Sullivan, 2010). Such risky behavior may also result from being coerced into sex or from fears of violent retaliation if she requests the use of protection.

Some partners also respond to a woman’s HIV diagnosis with violence. Although most partners are sympathetic and understanding when a woman discloses her HIV diagnosis, between 3% and 15% of women who disclosed their diagnosis reported that their partner responded with anger, blame, abandonment, and violence (World Health Organization [WHO], 2004b). One study found that disclosure to a partner triggered violence for 20.5% of HIV-infected women (Zierler et al., 2000). It appears disclosure interacts with additional psychosocial stressors (e.g., poverty, social isolation, drug dependence, homelessness, unemployment) to heighten a woman’s risk for IPV.

Women who are pregnant and HIV-positive are particularly vulnerable to violence. Most pregnant women exposed to violence have a prior history of partner violence, but a significant minority report
that it worsens during pregnancy (WHO, 2005). Over 90% of pregnant women who experience partner violence are abused by the biological father of the unborn child, and between 25% and 50% of those abused in pregnancy are kicked or punched in the abdomen (WHO, 2005). Poverty, drug use, and bartering sex, which are also associated with HIV infection, may further contribute to pregnant women’s exposure to violence. Unfortunately, despite the relationship between these two public health issues, relevant and comprehensive interventions addressing HIV and IPV are lacking (Gielen et al., 2007).

Mental Health

Mental health issues are highly prevalent among women with HIV. For example, women with HIV infection tend to have more depressive symptoms than HIV-negative women and twice the depression rates of HIV-positive men (Evans et al., 2002; Ickovics et al., 2001). HIV-infected African American women are especially at risk for depression compared to other ethnic groups (Lichtenstein, Laska, & Clair, 2002). Sometimes the distress for infected women is too great to bear. Despite declines in the last 20 years in the suicide rate among HIV-infected persons, the suicide mortality rate among HIV-infected women is over five times that of women in the general population (Keiser et al., 2010). Significant predictors of suicidal ideation and attempt among women with HIV/AIDS include stress associated with one’s diagnosis, psychiatric symptoms, physical or sexual abuse, and having children and being employed (Cooperman & Simoni, 2005). In contrast, suicidal ideation is negatively associated with spirituality. It is important, therefore, that women who test positive for HIV receive immediate counseling and support to help them understand and cope with their new status and circumstances (Cooperman & Simoni, 2005).

In addition to being at risk for suicide, women with HIV and depression have poorer daily functioning than infected women without mental health problems. For example, among HIV-infected mothers, depression, anxiety, and life stress are associated with poorer family cohesion, parenting, and child well-being (Murphy, 2009; Murphy, Greenwell, Resell, Brecht, & Schuster, 2008; Murphy, Marelich, Armistead, Herbeck, & Payne, 2010). Depressed mothers tend to be less attentive and protective toward their infants, have fewer positive interactions with their children, and provide a lower quality of environment (Cho, Holditch-Davis, & Miles, 2008; Holditch-Davis et al., 2001). Diminished maternal affect among these parents may put infants at heightened risk for attachment problems.

Similarly, poor parenting skills have been found among HIV-infected mothers who report high levels of stress and anxiety (Murphy et al., 2010). Parenting problems among anxious and stressed mothers included less consistent discipline, poor parent-child communication, and fewer family routines. High levels of psychological distress and poor parenting may lead to behavior problems in children (Bachanas, Kullgren, Schwartz, Lanier, et al., 2001; Klinkenberg & Sacks, 2004; McKee et al., 2007; Murphy et al., 2010; Reyland, McMahon, Higgins-Delessandro & Luthar, 2002). Children of HIV-infected parents may also be forced to assume caretaking roles because of their mother’s illness, leading to more absences from school, lowered school performance, and overall distress (Murphy et al., 2008). On the other hand, Murphy et al. (2008) found that this “parentification” of young children also predicts greater autonomy in adolescence, particularly when the child has a close attachment to the mother and good coping self-efficacy.
Major emotional and behavioral disturbances are also seen in children with HIV. HIV-infected children are more likely to exhibit attention deficit/hyperactivity disorder, oppositional defiant disorder, anxiety, depression, and problems in social functioning relative to their healthy peers (Bachanas, Kullgren, Schwartz, McDaniel, et al., 2001; Mellins, Smith et al., 2003; Steele, Nelson, & Cole, 2007). Children living with HIV also have concerns about their health and future, including worries about death. In addition, since almost all mothers of these children are also HIV-infected, the children must cope with the potential or actual loss of a parent (Bachanas, Kullgren, Schwartz, Lanier, et al., 2001; Steele et al., 2007).

However, studies have also found that some of the psychosocial problems faced by HIV-infected children are not significantly different from those of their non-infected peers from similar social backgrounds (Bachanas, Kullgren, Schwartz, Lanier, et al., 2001). For example, Mellins, Smith, and colleagues (2003) found that the high rate of behavioral problems in children with HIV was not significantly associated with HIV disease; instead, the problems were more consistently related to other demographic and environmental factors. Another study also found similar rates of psychiatric symptoms and impairment among HIV-infected and non-infected youth, although HIV-infected youth were more likely to receive mental health treatment (Chernoff et al., 2009).

Uninfected children in HIV-affected families also experience a range of mental health issues and face greater challenges to their psychosocial well-being compared to children of the same age who are not affected (King, DeSilva, Stein, & Patel, 2009). The impact of HIV on children may depend on a number of maternal factors, including health status, mental health, parental coping and parenting skills, disclosure of HIV status, and perceived HIV-related stigma. For example, children have fewer depressive symptoms and higher levels of satisfaction when their mothers are physically healthy, highlighting the importance of treatment among HIV-infected mothers (Murphy, 2009). Also, parenting skills, including parental monitoring and creating family routines, can foster child resilience (Murphy et al., 2008). These parenting skills, especially parental monitoring, can also help prevent adolescents from engaging in risky sexual behavior, thereby protecting them from contracting or spreading HIV (DiClemente et al., 2001).

### Substance Use

Substance use disorders are a significant problem among many women with HIV/AIDS. Though more women are infected through sexual contact, injection drug use remains a route of infection for some women. More generally, drug abuse is associated with behaviors that increase HIV risk, including trading sex for drugs or money, or engaging in high-risk sexual behavior due to impaired judgment associated with drug intoxication (Malow, Devieux, Rosenberg, Dyer, & St. Lawrence, 2006). Once infected, nearly 20% of women drink excessively, defined as a history of drinking four or more alcoholic drinks per day or seven or more alcoholic drinks per week (Cook et al., 2009).

HIV-infected women with co-occurring substance use disorders face additional challenges surrounding HIV/AIDS care and treatment. They are less likely to use medications prescribed for their HIV infection, they confront more barriers to treatment, and they experience poorer HIV-related health outcomes than HIV-infected women without substance abuse (Cook et al., 2002; Klinkenberg & Sacks,
Furthermore, serious interactions between recreational drugs and antiretroviral drugs have occurred that render the antiretroviral drugs ineffective or increase the level of recreational drugs in the system to fatal levels (The AIDS InfoNet, 2011).

**Grief and Loss**

Despite advances in HIV treatment and a reduction in AIDS-related deaths, families will continue to lose loved ones to AIDS. The severity of grief is elevated when the loved one is very close to the bereaved, when the bereaved has an existing substance use or mental health problem, and when he or she lacks social support. Bereaved women are particularly concerned about loss and coping issues related to their children, deceased partners or spouses, and family responsibilities (Sikkema, Hansen, Kochman, Tate, & DiFranceisco, 2004). They are also likely to experience both depression and traumatic stress. Grief may be particularly complicated for survivors with HIV, because they so far have responded more successfully to treatment than their loved ones (Sikkema, Kochman, DiFranceisco, Kelly, & Hoffman, 2003).

Many children with HIV must deal with the loss of one or both parents to AIDS, and their psychosocial needs are often overlooked (Close & Rigamonti, 2007). In response to the death, young people may display cognitive, physical, emotional, behavioral, spiritual, and social difficulties, and require more attention from adults. In addition to facing the death of a parent, many HIV-infected children must confront their own mortality. This can bring about fear and a loss of control, leading to withdrawn or irritable behaviors. Children with HIV need support to understand and cope with their futures. They can become empowered if they are given a role in making decisions affecting their lives (Close & Rigamonti, 2007).

**Stigma and Discrimination**

Societal and cultural stigma against persons with HIV/AIDS continues to abound and negatively impact the daily lives of infected persons. One survey found that 38% of infected persons feel that others judge them on the basis of their HIV status, and almost half reported that people avoid even casual contact with them, such as sharing food or drink, due to their infection (Solomon, 2010).

Stigma and discrimination contribute to infected women’s vulnerability by inhibiting them from seeking help and support for their condition. As perceived stigma increases, people become less likely to disclose their status (Clark, Lindner, Armistead, & Austin, 2004). Many HIV-infected individuals have voiced fears that disclosure would disrupt their current or future relationships, reputation, or employment status. Disclosure is often avoided because women fear abandonment, rejection, discrimination, or upsetting family members (WHO, 2004a).

In part because of the stigma and discrimination they experience, many people with HIV feel socially isolated (Fife & Wright, 2000). Women, particularly African American women, appear most affected by such rejection (Lichtenstein et al., 2002). Some scholars suggest that ethnic differences in feelings of isolation are due to the multiple layers of stigma that minority women with HIV/AIDS face (Henkel, Brown, & Kalichman, 2008).
Stigma can also negatively impact the children of mothers with HIV. Children who perceive stigma associated with their mother’s HIV status are more likely to engage in externalizing behaviors, including bullying and physical violence (Murphy, Austin, & Greenwell, 2006). Stigma surrounding the disease may also damage feelings of self-worth and discourage children from reaching out for social support (Close & Rigamonti, 2007). To help protect children with HIV from such stigma, some parents delay disclosing their status or treat it with secrecy. Ironically, wrapping the disease in secrecy may actually increase the stigma attached to it (Close & Rigamonti, 2007).

**DISCLOSURE**

Deciding whether and to whom to disclose their HIV status is an important issue persons with HIV must consider. Having a strong social support network can help women develop the confidence to disclose (Murphy, 2009; Simoni, Demas, Mason, Drossman, & Davis, 2000). Fortunately, for most women, people tend to respond to disclosure more positively than expected (WHO, 2004a). Some research suggests that disclosure can actually elicit emotional support and strengthen relationships. Disclosure to a sexual partner may motivate him to be tested, seek necessary medical treatment, or alter his behavior to decrease the transmission of HIV. Furthermore, women who disclose are more likely to obtain HIV-related services (WHO, 2004a).

A mother’s disclosure of her diagnosis to her children can be particularly important to address, as it may affect child adjustment and the mother–child relationship. The decision to disclose to children involves weighing the pros and cons of disclosing. It is often based on the child’s perceived ability to handle the information without being psychologically harmed (Delaney, Serovich, & Lim, 2008). One study found that half of the children of HIV-infected mothers reacted in a primarily positive manner to disclosure, while 40% reacted negatively (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001). Those responding negatively to disclosure expressed fear, anger, or rejection. Mothers may choose not to disclose to their children to avoid such negative responses, but research shows children are actually better adjusted when they are aware of their mother’s HIV status (Murphy et al., 2006). Even if children are not informed of the diagnosis, they may intuitively know something is wrong with their mother or notice her taking medications. Unaware of the reasons for the changes they see, children may feel anxiety or confusion (Murphy, Steers, & Dello Stritto, 2001). Open, honest communication between parents and children can facilitate positive experiences with disclosure, and allow children an opportunity to grieve or clarify any questions they may have regarding HIV (Delaney et al., 2008).

Similarly, the psychosocial functioning of a child infected with HIV can be improved by disclosure of the diagnosis to the child (Steele et al., 2007). Clinicians can encourage parents to use developmentally appropriate language and visual aids to help children understand their illness (New York State Department of Health AIDS Institute, 2009). Children may initially respond negatively to disclosure, but parents and health care providers can help children adjust to their diagnosis by validating their emotional responses, clarifying any misperceptions they have about the disease, and providing emotional support.
LEGAL ISSUES

Compounding the medical, financial, and emotional stresses faced by HIV-infected women are the legal concerns that also emerge. Fortunately, many areas in the country have low-cost or free legal resources specifically for persons with HIV/AIDS.

One set of legal issues HIV-infected mothers must grapple with pertains to how their medical condition impacts their current and future ability to provide care for their children. A mother may choose to appoint another adult to assume custody and care for her child or children in the event that she becomes too ill or dies as a result of her condition. In select states, she may designate a standby guardian, who has authority over the child once the parent is no longer able to provide the caretaking (Child Welfare Information Gateway, 2008). Appointing a standby or legal guardian usually requires a written petition and court hearing. Even when a standby guardian is designated, the parent shares in decision-making until he or she becomes incapacitated. Upon the triggering event, the standby guardian applies for permanent guardianship. In 2000, Illinois became the first state to enact standby adoption, a policy similar to standby guardianship, but that allows parents to petition for the appointment of an adoptive parent who stands by until the triggering event (Webber, 2010).

Making custody and care plans gives parents the power to determine who will care for their children. Permanency planning may require a mother to disclose her status to other adults, which is challenging for some (Coon & Curran, 2009). She may worry that her disclosure will be shared in open court, putting her at risk of losing her job, housing, or insurance. Custody planning may also require notification of the child’s other parent; a woman may fear this notification will lead to violence, resistance, or retaliation from the other parent. Custody planning also forces a woman to face her own mortality directly. Because of these potential issues, workers should inform clients of their options and allow them to begin the permanency planning process on their own terms (National Abandoned Infants Assistance Resource Center [NAIARC], 2007).

Some families affected by HIV may have other legal needs, including cases of discrimination in hiring, wages, or housing. Women may also need assistance in applying for public benefits or appealing these decisions. Although Congress voted to remove the ban on HIV-infected non-citizens becoming residents in 2009, some HIV-infected women may worry about issues related to immigration, political asylum, suspension of deportation, and naturalization (Immigration Equality, 2010).

Women with HIV may also need legal representation to deal with breaches of confidentiality. Health providers must consider and respect a woman’s right to privacy and confidentiality at all times. State confidentiality laws vary, but the federal health information privacy law (HIPAA) mandates disclosure only for treatment purposes (Palmer & Mickelson, 2001). Therefore, there is no need for most people to reveal their HIV status in the workplace. If the disease happens to interfere with workplace productivity, an employee may notify a supervisor that she has a disabling condition. She is then protected by the Americans with Disabilities Act from discrimination and may be offered reasonable accommodations to continue working (Palmer & Mickelson, 2001).
HIV TREATMENT

There is no cure for HIV/AIDS, but HAART can keep it in check. The goals of HIV treatment should be to “reduce HIV-associated morbidity and prolong the duration and quality of survival, restore and preserve immunologic function, maximally and durably suppress plasma HIV viral load...and prevent HIV transmission” (Panel on Antiretroviral Guidelines for Adults and Adolescents [PAGAA], 2011, p. 24).

Medications

For those just starting medications, the simplicity and effectiveness of treatment is a primary consideration. Medications can help the infected person live a longer, healthier life, but they are less effective if they are not taken as prescribed. Patient adherence to the medication regimen remains a critical component of successful HIV treatment and AIDS prophylaxis. In fact, adherence has been found to predict long-term treatment success, whereas non-adherence is associated with viral resistance, which is more complicated to treat and requires much more medication (PAGAA, 2011). Unfortunately, adherence can be challenging because of regime complexity and because many of the medications can cause serious side effects until the body becomes used to them. Side effects can include nausea and vomiting, diarrhea, rash, insomnia, fatigue, psychiatric symptoms, and elevated cholesterol and triglyceride levels (Avert, 2011).

Research has found that depressive symptoms, poor quality of life, and other psychosocial stressors reduce the likelihood that a woman will take her antiretroviral drugs as prescribed (Cook et al., 2002; Kacanek et al., 2010; Mellins, Kang, Leu, Havens, & Chesney, 2003). Other prominent factors associated with non-adherence include fear of both short- and long-term side effects, interactions with other drugs, limited knowledge about HIV and treatment issues (Canadian AIDS Treatment Information Exchange, 2002), social stigma (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006), the severity of physical symptoms, and beliefs about medication (Gonzalez et al., 2007).

Adolescents face additional barriers to adherence as they begin taking responsibility for their own medication regimens. Perceived social stigma, busy schedules, and body image issues that can arise from medication side effects may interfere with adherence. Health and mental health problems, academic difficulties, and experiencing recent stressful events also lead to non-adherence (Malee et al., 2009; Williams et al., 2006). Furthermore, perinatally infected patients who have developed HIV drug resistance may need “salvage” therapy, which typically requires taking many pills twice a day, posing even greater adherence challenges (Hazra, Siberry, & Mofenson, 2010). Finally, factors such as poor parent-child communication, higher caregiver stress, and lower quality of life among caregivers predict missed dosages of medication among both children and caregivers (Mellins, Brackis-Scott, Dolezal, & Abrams, 2004). To address and improve treatment adherence among children, the broader context of children’s lives must be considered, including caregiver needs and characteristics (Mellins et al., 2004).

Although persons with HIV face many barriers to treatment adherence, factors positively associated with adherence include knowledge about the importance of adherence, integration of treatment into
the routine of everyday life, and social support for adherence (Canadian AIDS Treatment Information Exchange, 2002). Thus, strategies to increase medication adherence include education about the importance of adherence for the prevention of HIV transmission; reminder systems, such as beepers and pillboxes; regimen simplification; monitoring and addressing barriers to adherence; and tailoring solutions based on the unique challenges faced by individual patients (Ickovics et al., 2001). Some research indicates that motivational interviewing, cognitive-behavioral therapy, or couple-based interventions may also help improve medication adherence (Parsons, Golub, Rosof, & Holder, 2007; Remien et al., 2005).

**Non-medical Interventions**

Research suggests that effective interventions with HIV-infected mothers and their families promote positive parenting and problem-solving skills, address the numerous stressors they face, and help them build social support to cope with their illness and motherhood. No single program or profession can provide the breadth of services required by these families. Multidisciplinary treatment teams are essential to address the diverse needs of families affected by HIV/AIDS from medical and behavioral health to social support, developmental services, and legal assistance. Interdisciplinary and multi-agency collaboration happens at many junctures in service provision: in clinical practice; on home visits; in clinics; and at care planning conferences.

**Culturally relevant services**

As with any effective social work intervention, particular attention must be paid to cultural issues in serving families affected by HIV/AIDS. Programs should offer multicultural staff; bilingual client materials; therapeutic approaches and curricula that are respectful and accepted locally; staff training on cultural sensitivity; and services that involve clients and partners. Given the high rates of HIV/AIDS among African Americans and Latinos, specific interventions tailored to the unique needs of these populations are critical.

Several types of interventions may be most appropriate for African American families affected by HIV. For example, those that incorporate faith and spirituality and that are family rather than individually based, are often most effective for African American women (Ardly & Sileo, 2009; MacMaster et al., 2007; Pietrzak, 2009). Such approaches may ease psychological distress and family-related disputes (Szapocznik et al., 2004). Interventions for this population should also draw upon the strength of a woman’s social network and bolster ethnic pride and positive self-esteem (Owens, 2003). This is because social networks, including extended family, community members, and friends, often serve as a powerful source of support for African American women. All strategies should empower African American women and their families to make their own choices in an effort to restore self-efficacy and self-esteem.

It is important that interventions for Latino families give special attention to cultural issues as well. HIV/AIDS often carries a profound stigma in Latino culture. Therefore, Latinas with HIV are reluctant to disclose their HIV status or seek treatment for a number of reasons, including fear that they will be perceived as promiscuous or substance users, fear of intimate partner violence, and perceived threat of deportation. Programs serving Latinas should provide help in coping with perceived stigma;
address traditional cultural beliefs that pose barriers to disclosure; and counteract mothers’ beliefs that they have not lived up to the archetype of ideal motherhood. They should also adopt service strategies that reflect universal Latino cultural values and beliefs, such as honoring the family (Pietrzak, 2009).

**Family-based interventions**

Family-centered approaches are commonly accepted as the most suitable, effective models for providing services to families affected by HIV. Given the social, economic, and psychological challenges faced by families living with HIV infection and AIDS, it is important to offer services that address these issues and nurture the relationship between mothers and families living with HIV/AIDS. Home-based services are especially valued because they sidestep common barriers to services, namely childcare, transportation, and financial challenges, and they give the clinician an accurate portrayal of household and family dynamics (NAIARC, 2003). Key to any family work is a long-term, trusting, nonjudgmental relationship between the family and service providers.

**Strength-based interventions**

While families affected by HIV/AIDS often confront significant and prolonged difficulties, many also have protective factors that may be tapped to improve their psychological, social, and health outcomes. For example, pregnant women with HIV/AIDS may view childbirth as an opportunity to adopt a healthier lifestyle; this may be the moment when a woman finally accepts professional help to manage her illness and make positive changes. Some families will develop strong social ties with other families who are impacted by HIV/AIDS; these alliances can offer support, resources, and help. Thus, to optimize care, HIV/AIDS providers should be aware of, and build upon, the strengths families bring to treatment.

**Family involvement in assessment and treatment**

Interventions should be developed in partnership with the client families. Rather than prescribing goals and enforcing them, staff members need to support clients to set and reach their own goals. Interventions with families often begin with a period of comprehensive assessments, including infant and child development evaluations, social support and parenting scales, and community needs and gaps assessments. This thorough assessment process solicits a family’s perspective, identifies the specialized needs and circumstances of the family, and informs family-centered goal setting, which is the core of the intervention.

**Case management**

Case management, or case coordination, works as a powerful therapeutic tool in programs. Case managers assist families in identifying their needs, developing goals, and obtaining services. Thereafter, they coordinate and follow up with interdisciplinary team members to ensure the family has access to the full array of needed services. Although case managers offer some oversight of treatment, everyone on the team assumes responsibility for ongoing monitoring of the child or children, and addresses any potential risk factors that hinder a child’s growth and development.
Individual counseling

Some HIV-infected women may benefit from individual therapy. In general, counselors should collaborate with other mental health and medical providers; provide risk and harm reduction counseling to minimize the spread of HIV; ensure a client’s concrete needs are met; prepare the client for the possibility of disability, death, and dying; and educate significant others about how to care for and support the client. The counselor may also normalize the client’s emotions, teach healthy coping strategies, and encourage the use of friends and family as supports.

Several specific therapeutic techniques have been shown to help persons infected with HIV successfully cope with their illness. For instance, cognitive-behavioral therapy can help with countering dysfunctional thoughts, improving mood, changing self-destructive behaviors, and improving medication adherence (Safren et al., 2004). Motivational interviewing is another method that can be used to reduce risky behavior. This approach consists of individual counseling sessions in which the woman identifies episodes of risky behavior, such as substance use and unprotected sexual activity; assesses her readiness to reduce these behaviors; and discusses her ambivalence about behavior change. Some research indicates that combining motivational interviewing with cognitive-behavioral therapy is a particularly effective treatment for HIV-infected adults with substance use disorders (Parsons, Rosof, Punzalan, & DiMaria, 2005).

Support groups and group counseling

In addition to individual therapy, group counseling for women and adolescents with HIV/AIDS can be helpful in treating depression, reducing social isolation, increasing coping resources, and obtaining support (Funck-Brentano et al., 2005; Himelhoch, Medoff, & Oyeniyi, 2007). Groups are helpful because people often feel relief when they learn that others have had the same experiences. Listening to others’ challenges can offer a woman a better perspective on her own problems and help her learn new ways to cope with her illness. Group therapy has also been shown to improve mood, relationships, and medical outcomes (Belanoff et al., 2005; Funck-Brentano et al., 2005). One successful women’s group focused on exploring views of the self, learning to identify and express feelings, trying new behaviors, identifying life goals and values, discovering strengths, and developing interpersonal skills and relationships (Stewart & Dixon-Andersen, 2010). Group interventions that utilize cognitive-behavioral approaches have been particularly successful in improving mental health outcomes for women (Sikkema et al., 2004). These groups help with developing social support, identifying and expressing emotions, identifying coping challenges, recognizing stressors, setting goals, and developing adaptive coping skills to reduce psychological distress. Women participating in such groups demonstrate greater improvement on measures of anxiety, depression, and grief.

Substance abuse assessment and treatment

The pronounced link between substance use and HIV/AIDS has prompted some experts to recommend screening patients for drug use at the initial HIV diagnosis and at least annually thereafter (New York State Department of Health AIDS Institute, 2007). Screenings should inquire about the most commonly used recreational drugs, be tailored and adjusted for the client’s substance use history, and be conducted in a nonjudgmental manner. Preventing HIV transmission among those with substance use disorders involves treating users with respect; educating them about how they can
change their behavior to reduce transmission; and providing them with the means for change, including access to clean needles, condoms, and drug abuse treatment (Jarlais & Semaan, 2008). Community-based outreach, peer-based interventions, skills building, and individual and group counseling are among the approaches that may successfully reduce the risk of HIV transmission among substance using populations.

**FEDERAL PROGRAMS AND SERVICES**

The federal government has made a long-standing commitment to assist families affected by HIV and AIDS in the United States. The Ryan White Comprehensive AIDS Resources Emergency—or CARE Act of 1990—established a program that helps provide care for people with HIV/AIDS. After Medicare and Medicaid, it is the largest source of public financing for HIV/AIDS care. The Act is divided into several parts, including Part D (previously called Title IV), through which a comprehensive care system has been developed for women, infants, children, youth, and their families (HIV/AIDS Bureau, 2005; The Kaiser Family Foundation, 2006). Research has demonstrated the effectiveness of this comprehensive and coordinated approach in delivering HIV treatment (HIV/AIDS Bureau, 2004). Part F of the Ryan White Program includes funding that goes to Special Projects of National Significance (SPNS), a program that promotes the dissemination and replication of effective HIV care to special and hard-to-reach populations, such as the homeless, adolescents, and substance users (U.S. DHHS, n.d.). SPNS also supports the development and evaluation of innovative services. One of its current projects is a multi-site demonstration and evaluation of interventions that aim to improve access to and retention in care for women of color.

Since 1990, the Children’s Bureau of the U.S. DHHS, has provided grant funding under the Abandoned Infants Assistance or AIA program, another source of support to projects working with families affected by HIV/AIDS. AIA projects have found that the most effective services for these families are family-centered, culturally-based, comprehensive, coordinated, and individualized; emphasize employability, self-sufficiency skills, education; and offer supports for basic needs (Fuger, Abel, & Stephens, 2010).

The White House has established clear goals for improving the national response to the HIV/AIDS epidemic. In July 2010, the White House’s Office of National AIDS Policy (2010) released its National HIV/AIDS Strategy, which outlines three primary goals: (1) reduce the number of people who become infected with HIV, (2) increase access to care and optimize health outcomes for people living with HIV, and (3) reduce HIV-related health disparities. To help accomplish these goals, various federal agencies conduct HIV/AIDS-related research, prevention, and intervention activities. For example, the National Institutes of Health (NIH) performs research in a variety of HIV-related areas, including etiology, therapeutics, vaccines, behavioral interventions, and the impact of HIV/AIDS on specific populations (NIH, 2009). The Substance Abuse and Mental Health Services Administration (SAMHSA, 2009) studies how substance abuse influences the spread of HIV and aims to increase access to HIV prevention, care, and treatment. This agency has also been called on to ensure routine HIV testing is offered at substance abuse and mental health treatment centers (The White House Office of National AIDS Policy, 2010).
Finally, in addition to its surveillance activities, the CDC funds the Diffusion of Effective Behavioral Interventions (DEBI) program, which provides training, technical assistance, and other resources needed to help State and local health departments and community-based agencies carry out evidence-based HIV interventions (CDC, 2009a; Collins, Harshbarger, Sawyer, & Hamdallah, 2006). The goals of DEBI are: 1) to enhance health department and agency capacity to design and implement evidence-based interventions, 2) reduce rates of hepatitis, HIV, and sexually transmitted diseases, 3) encourage healthy behaviors among clients, and 4) build clients’ skills and resources (Collins et al., 2006). Ideally, the needs, culture, and values of the community are considered when interventions are disseminated (Dworkin, Pinto, Hunter, Rapkin, & Remien, 2008). For example, Prather and colleagues (2006) recommended Afrocentric and gender-specific approaches, such as those used in the DEBI-approved Sisters Informing Sisters About Topics on AIDS (SISTA) intervention, for addressing HIV among African American women.

CONCLUSION

Advances in antiretroviral therapies have offered considerable benefits in maternal and child health, most notably by reducing the number of deaths due to HIV and the rates of MTCT. The introduction of accurate rapid HIV testing provides a promising avenue to help prevent maternal transmission and improve the overall process of counseling and testing. In addition, case management and coordinated services have proven to be successful interventions in addressing the needs of families affected by HIV.

HIV, nevertheless, continues to be a significant problem affecting women and children in the U.S., particularly in African American and Latina communities. More women and children are living with HIV today than at any time since the beginning of the epidemic, and they require long-term and complex medical care and treatments. In addition to coping with a chronic and life-threatening illness, HIV-affected families often face an array of other taxing issues, including poverty, inadequate housing, depression, substance abuse, violence, and future care and custody planning. Families continue to need comprehensive services to effectively address these issues.

A one-size-fits-all approach will not be sufficient to address the needs of infected women and children and curb the spread of HIV/AIDS. In particular, client input and cultural issues must be considered when developing interventions. Moreover, further research should be sponsored and conducted to ensure that services provided to HIV-affected families are evidence-informed. To effectively address racial and gender disparities, HIV prevention and intervention efforts should take into account the myriad factors infected women and children face on both an individual and societal level.
REFERENCES


The publication of this fact sheet was made possible by #90-CB-0177 from the Children’s Bureau, Administration on Children, Youth and Families, Administration for Children and Families, U.S. Department of Health and Human Services. The contents are solely the responsibility of the authors and do not represent the official views or policies of the funding agency. Publication does not in any way constitute an endorsement by the Department of Health and Human Services. Readers are encouraged to copy and share this material, but please credit the National AIA Resource Center.