

# PSYCHOSOCIAL ASPECTS OF HIV/AIDS: CHILDREN & ADOLESCENTS

# PSYCHOSOCIAL CHILDREN & ADOLESCENTS

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## Objectives

The purposes of this module are to:

1. Identify psychosocial factors that affect children and adolescents infected with HIV/AIDS and how these factors relate to general chronic illness.
2. Identify sources of stigma and discrimination against children and adolescents and explore how stigma affects disclosure.
3. Examine issues of death and dying and the grief/bereavement process that follows for survivors.
4. Identify particularly vulnerable pediatric and adolescent populations and explore reasons why they are at increased risk of HIV/AIDS infection and progression.
5. Discuss special issues encountered by adolescents.

contracting HIV/AIDS and of receiving less support during their illness.

5. Adolescents are a unique population with a pivotal role in the future of the pandemic. They need special care and attention, including support and education.

## Overview

HIV/AIDS takes an enormous physical toll on those infected by the virus as well as those who care for them. However, the psychological toll of the epidemic is just as significant. The psychological and social effects of HIV/AIDS are magnified in young people. Children and adolescents are an ever-growing part of the HIV/AIDS epidemic. In 2004, an estimated 2.2 million children under the age of 15 were living with HIV.<sup>1</sup>

Children involved in the epidemic face a set of psychological and social issues that must be addressed, not overlooked. This chapter will discuss how children and adolescents are affected by some of the important aspects of the HIV/AIDS epidemic, including stigma, disclosure, and death, and how health care professionals can support them in dealing with these challenges.

## Key Points

1. HIV/AIDS progresses through many of the stages and stresses of other pediatric chronic and terminal illnesses.
2. Stigma affects all aspects of caring for children and adolescents infected and affected by HIV/AIDS, especially as they face the issue of disclosure.
3. Death and bereavement are important topics to help children deal with, even at an early age.
4. Orphans and girls are at increased risk of

## HIV/AIDS as a Chronic Illness

In many parts of the world, HIV/AIDS is still seen as a death sentence, a disease from which there is no recovery. But with the ever-improving availability of antiretroviral therapy, HIV is increasingly recognized as a chronic rather than terminal illness. This transition requires psychological adjustments, especially in the pediatric and adolescent populations.

A chronic illness can be defined as “a disorder with a protracted course which can be progressive and fatal or associated with a relatively normal life span despite impaired mental and/or physical functioning.”<sup>2</sup> This broad definition encompasses multiple types of conditions, ranging from fatal to lifelong. It includes HIV/AIDS, which can but need not be fatal. Unlike acute conditions, which normally develop and resolve themselves quickly, chronic conditions are lifelong and usually have no cure. Of the main characteristics experienced by children with chronic illnesses or conditions, children with HIV infection may experience:

- Limitation of developmentally appropriate functioning
- Dependency on medication
- Need for more medical care than is normal for their age
- Disfigurement resulting from certain opportunistic infections or severe wasting accompanying progressive disease.<sup>3</sup>

Because chronic illness persists for an extended time, affected children and their caregivers go through several stages that can be sources of great stress. These stages include:

- Initial diagnosis
- Disclosure to the child
- Difficulties resulting from long-term care, including financial and emotional strain
- Preparation for and acceptance of the patient’s eventual death.<sup>2</sup>

The stressors of a chronic illness are more challenging when the ill patient is a child. This increases the

necessity for primary caregivers and other family members to assist with medical care and with activities of daily living. Chronic illness creates a series of challenges for those involved in the child’s care. These challenges fall into three general areas: emotional, cognitive, and behavioral. Emotionally, the family must come to terms with the child’s diagnosis. This includes grief over the loss of the “idea” of their once-healthy child, as well as guilt, sadness, and anger. If the child was infected with HIV through mother-to-child transmission, the mother may feel enormous guilt and may even be blamed within the family for the child’s diagnosis.

The cognitive challenge is to educate the child’s family about HIV/AIDS, including transmission, disease progression, and treatment. Family members must understand how the child’s life will be affected on a daily basis. They must also understand the importance of adherence to the prescribed medication regimen. If they understand how the medications work, family members can become an informed asset to the team providing the child’s medical care. The family should also be educated regarding the symptoms of disease progression and possible side effects of medications. This way the family will know what to look for if the child falls ill or develops new symptoms.

The behavioral challenge consists of incorporating the child’s chronic illness in the daily life of the child and the family. Amidst the required behavioral changes, the child’s caregivers must also try to maintain a sense of normalcy for the child. The child’s medications and clinic visits need to be a part of daily living, though they often require major adjustments and place a strain on family relationships and routines. To develop as fully as possible, the child still needs rules, discipline, and routines. Routines are especially important for children dealing with stressful or new situations, because they help provide a sense of security.

Children with a chronic illness such as HIV/AIDS face unique challenges that make their lives more difficult. It is important to understand the long-term

effects these challenges can have on the children and their caregivers, whether that's their parents, extended family, or others in the community. With proper support from their health care providers and their community, the burden of childhood with HIV/AIDS will seem less great.

## HIV/AIDS and Stigma

A major factor that distinguishes HIV/AIDS from other chronic or terminal illnesses is the stigma associated with the disease. This stigma comes from a lack of knowledge about HIV and how it is transmitted. Stigma can adversely affect children and their caregivers in ways that have long-term negative psychological and social effects.

Stigma can be defined as “a negative, moral, or judgmental definition of a person or social situation, often connected to discredit, disgrace, blame, and ascription of responsibility for the conditions.”<sup>4</sup> Stigma alters the way people perceive and interact with the world around them. Stigma can have such a profound effect that it changes the way people think and feel about themselves. Stigma surrounding HIV/AIDS is not particular to one generation or one part of the world; it has been an important aspect of the disease since the first cases emerged in the early 1980s, and it has taken hold in all areas, even those untouched by the mass media.

HIV/AIDS stigma originated in the association of the disease with homosexual men and intravenous drug users, two marginalized groups in which the disease first came to public attention. Though beliefs that transmission was limited to these groups were soon proven false, stigma persisted and was reinforced by moral judgments of sexual promiscuity as a cause of transmission. Among some people, these associations have resisted widespread HIV education. HIV/AIDS stigma may be facilitated by the fact that the disease can be fatal, has no cure, and has noticeable physical effects during its advanced stages.<sup>5</sup>

The pediatric population was not a prominent part of the initial phase of the pandemic.<sup>6</sup> In the beginning, few children were recognized as being infected. The first groups of HIV-positive children to be recognized were those who had received infected blood products, particularly young boys with hemophilia, and children born to HIV-positive mothers. Today, those infected through mother-to-child transmission make up the vast majority of HIV-positive patients under the age of 15. Infection among adolescents (ages 15-24) is growing at an astounding rate, mostly through sexual transmission.

Three concepts are helpful in understanding stigma as it relates to the pediatric population: associative stigma, internalized stigma, and stigma management. Stigma is associative when it affects people because of their association with a stigmatized person (in this case, a person with HIV or AIDS).<sup>4</sup> Associative stigma may affect caregivers who step in and help care for infected or affected children whose parents have died. Children may be affected by associative stigma if their parents are publicly known to be infected with HIV.

Stigma takes a particularly damaging form when it becomes internalized, which occurs when a person is aware of a social stigma and accepts, or internalizes, society's negative views. This damages the person's self-esteem and gives him or her a negative sense of self-worth.<sup>4</sup> Internalized stigma has a big impact on the pediatric population through its influence on parents' decisions about disclosure. If parents or caregivers have internalized the stigma and negative views of HIV/AIDS, their likelihood of telling the child about his or her diagnosis decreases significantly. If adolescents internalize the stigma regarding their diagnosis, they are more likely to become depressed and engage in denial regarding their HIV status.

Stigma management is a way of coping with HIV/AIDS stigma by being aware of possible negative reactions and finding ways to minimize them.<sup>4</sup> Children who know their diagnosis may practice stigma management by choosing and limiting whom

they disclose to in order to minimize the chance of negative reactions or rejection.

Stigma surrounding HIV/AIDS can severely impact those infected or affected by the virus. Prone to both stigma internalization and stigma management, they are less likely to seek social support for fear of rejection and isolation. In some areas, stigma has been reduced through education and outreach. In many parts of the world, however, stigma is still a harsh reality, sometimes barring children from school and other community activities. To safeguard a child from experiencing stigma, caregivers may delay disclosing the child's diagnosis to the child; if children are unaware of their diagnosis, they are less likely to tell the "wrong" people. Data show that between 25 percent and 90 percent of school-aged HIV-positive children are unaware of their own HIV status.<sup>7</sup> Many caregivers feel that if children know their diagnosis, they will internalize the stigma and give up. In this way, stigma leads to an atmosphere of secrecy within the family that the child often senses. Labeling the diagnosis a secret that must not be discussed only serves to increase the stigma. Many parents also are afraid to disclose the child's HIV-positive status because of deep feelings of guilt or shame, especially when the route of transmission was from mother to child. The parents may feel guilty about their role in infecting the child and fear that the child will become angry or blame them.

These families need to be supported and educated, along with their communities. Through basic education about the virus and how it is transmitted, much of the stigma can be dispelled. With knowledge, long-standing myths and rumors can be laid to rest and the truth regarding HIV can replace fear and ignorance. Through support, families and children infected and affected by the HIV/AIDS epidemic will no longer feel alone in their struggle.

## Death and Bereavement

Despite the increased availability of highly active antiretroviral therapy (HAART), death is still a

common outcome of HIV/AIDS. Each year, millions of children lose one or both parents to AIDS. While relatives go to heroic lengths to provide orphans with food, shelter, and housing, oftentimes the children's psychosocial needs are overlooked, and the children are not given full recognition or support after their loss. This is usually due to the belief that children are too young to understand what is happening or are better off not dwelling on their loss. Consequently, children are not properly supported in their time of mourning.

When a parent or caregiver approaches the end stages of AIDS, it is extremely important that a plan of care be created for the children. This is referred to as permanency planning. When this step is not taken, children are left in a state of uncertainty about who will care for them. This can compound the loss felt by the child after a parent's death. The child may be separated from siblings and may experience frequent shifts from place to place in search of a proper home.<sup>8</sup> Children whose parents do not complete permanency planning are at increased risk of developing emotional and behavioral problems.<sup>9</sup>

For children who have lost parents or family members, grief can be overwhelming and hard to understand. Grief and bereavement experiences are unique to each individual. Grief can cause a series of different types of responses, including physical, emotional, behavioral, cognitive, spiritual, and social. Social responses are particularly important because of the high rate of stigmatization associated with HIV/AIDS.<sup>8</sup> It is also imperative that grieving children be able to acknowledge their loss and be provided with an opportunity to release their grief. Without such an opportunity, they may experience psychological ramifications well into adult and may indeed never recover from their loss.

It is common for children to experience a regression in their behavior during their period of mourning.<sup>8</sup> They may begin to display behaviors they have not exhibited in a long time, such as sucking on their

thumbs or becoming increasingly clingy – both actions that help increase their sense of security in a time of confusion. Some children will also try to gain attention through acting-out behaviors. Attention helps children remember they have not been forgotten. So children will act out to get this attention, even if the attention is negative in nature.

It is important to understand how children’s views death are shaped by their developmental age. For children 0-2 years of age, comprehension of death is very limited.<sup>8</sup> However, they realize that the deceased person is no longer in the environment. These children may be more irritable than usual and may exhibit clinging behaviors. From 3 to 5 years of age, orphans believe that the deceased parent is just away for the time being and will eventually return.<sup>8</sup> They have no comprehension of the finality of death.

Children ages 6-8 are curious and wonder what happened to the person who died.<sup>8</sup> They believe the person is still alive and functioning, wherever he or she is, and they may ask whether the person can return someday. Children of this age also begin to exhibit forms of “magical thinking,” in which they believe they have the power to affect things with their thoughts or actions that in reality are out of

their control. For example, a child who made his mother angry shortly before her death may believe he caused the mother’s death.

At ages 9-12, children come to realize that death is final and irreversible.<sup>8</sup> The loved one will not return. These children are concrete thinkers and have trouble comprehending anything beyond the physical death that has occurred. During this period, children may show aggressive tendencies, display risky behaviors, or become excessively impulsive. During adolescence, ages 13-18, youths understand the concrete nature of death and also begin to understand death in an abstract sense.<sup>8</sup> They think of death in terms of an afterlife as well as a physical death. Adolescents have powerful emotions regarding death and may exhibit these emotions for extended periods of time at random intervals. It may take years for a child to come to terms with parent’s death. (For more information on developmental stages and how children experience grief, see Table 1.)

For children of all ages, support is a key factor in the grieving process. This support can come from their families, friends, and communities. Rituals are a central part of death and grieving for communities around the world. Often children have assigned roles during such rituals. Sometimes participating in rituals

**Table 1: Children’s Developmental Stages of Grief<sup>8</sup>**

Age	Thoughts	Feelings	Actions
3-5 years	<ul style="list-style-type: none"> <li>Loved one will return.</li> <li>Loved one is just away.</li> </ul>	<ul style="list-style-type: none"> <li>Fearful of separation</li> <li>Anxious</li> <li>Confused</li> </ul>	<ul style="list-style-type: none"> <li>Cry</li> <li>Temper tantrums</li> <li>Nightmares</li> <li>Regressive/clingy behavior</li> </ul>
6-8 years	<ul style="list-style-type: none"> <li>Wonder if loved one can return</li> <li>Deceased can still function</li> <li>Magical thinking</li> </ul>	<ul style="list-style-type: none"> <li>Confused or anxious</li> <li>Fearful of separation</li> <li>Fearful they might die, too</li> </ul>	<ul style="list-style-type: none"> <li>Temper tantrums</li> <li>Nightmares</li> <li>Regressive/clingy behavior</li> <li>Difficulty concentrating</li> </ul>
9-12 years	<ul style="list-style-type: none"> <li>Understand finality and irreversibility of death</li> <li>Magical thinking</li> </ul>	<ul style="list-style-type: none"> <li>Sad</li> <li>Anxious</li> <li>Lonely</li> <li>Confused</li> <li>Withdrawn</li> </ul>	<ul style="list-style-type: none"> <li>Aggressive/impulsive behavior</li> <li>Engage in risky behavior</li> <li>Decline in school performance</li> <li>Difficulty concentrating</li> </ul>
13-18 years	<ul style="list-style-type: none"> <li>Understand finality of death</li> <li>Begin to look beyond physical death</li> <li>Magical thinking</li> </ul>	<ul style="list-style-type: none"> <li>Sad</li> <li>Anxious</li> <li>Lonely</li> <li>Confused</li> <li>Withdrawn</li> <li>Guilty</li> </ul>	<ul style="list-style-type: none"> <li>Aggressive/impulsive behavior</li> <li>Engage in risky behavior</li> <li>Decline in school performance</li> <li>Difficulty concentrating</li> <li>Exhibit powerful emotional bursts</li> </ul>

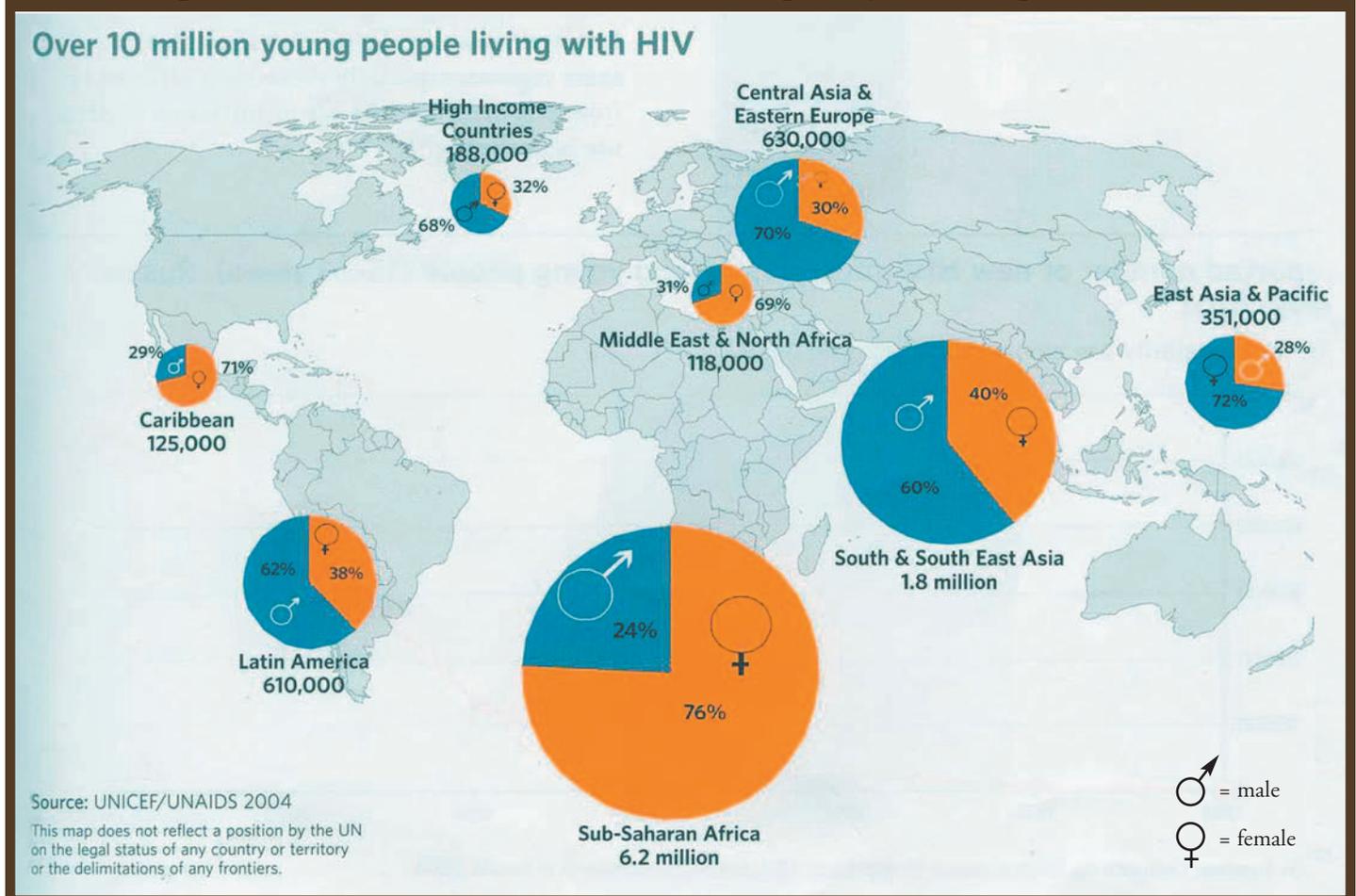
can help children with the transition and acceptance of a loved one's death. On the other hand, sometimes these roles can increase the trauma experienced by the child. Children must be supported before and after the ritual to reduce the amount of stress they experience. If participation in the ritual is optional, children should be allowed to choose whether they would like to participate.

When children face their own death, many experience anticipatory grief, "the grief expressed when the loss is perceived as inevitable".<sup>10</sup> Children may exhibit signs of anticipatory grief when they feel their death approaching. Often they will project their feelings onto others. For example, they may express fear that their caregivers might die. They will panic at the thought of anything traumatic happening to those persons, when in fact they are afraid of their own

death and what will happen to their loved ones when they are gone. They may also show signs of knowing about their fate through symbolic play or art, for example through pretending toys are dead or by drawing death in their artwork. Children may become withdrawn, quiet, and increasingly irritable.<sup>10</sup> They will inevitably feel a loss of control in the world around them.

To help children face this oncoming event, support is essential. Children must be given the opportunity to express what they are feeling and to ask questions about what might happen. These talks must be at a developmentally appropriate level so the child will understand. Children should be allowed to participate in decisions affecting them. They are the best resource for determining what they want and how much they can tolerate in the end stages of life.<sup>8</sup>

**Figure 1: More Than 10 Million Young People Living With HIV**



Source: UNICEF/UNAIDS 2004

Unfortunately, death and grief are harsh realities in this pandemic. Children's experience of losing parents and loved ones is often compounded by their own illness and by other factors surrounding the loss, such as secrecy and stigma. These families need additional support and care from their health care providers during their time of mourning.

## Orphans and Vulnerable Children

All children need food, clothing, safe shelter, health care, and education. Young children depend on parents and caregivers to provide them with these necessities. However, for millions of children whose parents have died of AIDS, survival and well-being are in jeopardy. About 15 million children under the age of 15 have lost one or both parents to AIDS, most of them living in sub-Saharan Africa.<sup>11</sup> By 2010, it is estimated that more than 25 million children around the world will be orphaned by the AIDS pandemic.<sup>11</sup> In addition, AIDS has caused children to experience the loss of their siblings, friends, relatives, teachers, doctors, and other significant people in their lives.

Besides experiencing multiples losses, children orphaned by AIDS are likely to suffer economic hardship, malnutrition, illness, and loss of property and inheritance. Older orphans may drop out of school to work or care for younger siblings. Feeling powerless and lost, some orphans end up living on the streets, trading sex for money or food. Others live in orphanages or institutions, which often fail to provide adequately for the physical and psychosocial needs of children. Institutions also cost more than direct monetary assistance to families that foster orphans. Recognizing the frequent poor outcomes and expense of long-term institutionalized care, several countries have chosen to support family-based care models rather than institutions.<sup>12</sup>

### Gender Issues

Worldwide, young women (ages 15-24) are 1.6 times as likely as young men to be HIV-positive, according

to the UNAIDS 2004 Report on the Global AIDS Epidemic. Figure 1 shows the gender ratios by region. In sub-Saharan Africa, young women are three times as likely as men to be HIV-positive. In many cases, young women may lack access to education and prevention programs due to sociocultural factors. In a survey in sub-Saharan Africa, half of the young women did not know that a healthy-looking person can have HIV.<sup>13</sup> In addition, UNICEF found that more than half of the adolescents surveyed in 17 countries could not name a single method of protecting themselves against HIV.<sup>14</sup> Sadly, many young women are coerced or forced into unprotected sex. A girl's vaginal tissue tears easily, putting her at high risk of contracting HIV from unprotected sex. Violence, forced prostitution, incest, and rape, including marital rape, all put girls and women at risk.

The story of 17-year-old Nicole and her 14-year-old brother, John, illustrates the many social challenges that orphaned and vulnerable children (OVC) face. The two live in the small, bleak apartment they once shared with their parents. John, infected vertically with HIV, receives excellent medical care and treatment at a nearby clinic. Nicole attends school, helps her brother with homework, and does all the household cooking and cleaning. Nicole's biggest fear is that without her care, John will die. Their uncle is trying to take their property and the small inheritance they have. They need legal aid but cannot afford to hire a lawyer. Nicole wants to attend school next year, too, but cannot afford the fees. Imagine a charming older man who is sexually experienced, possibly infected, pursuing Nicole with expensive gifts and hints of marriage. Would she choose to abstain, ask whether he's been tested, discuss whether he is faithful, or insist on condoms every time? In such situations, young women like Nicole may lack the confidence, power, knowledge, and skills to keep themselves safe.

In regions where the HIV epidemic is at an early stage, more young men than young women are infected. In Latin America, the epidemic is centered among men

who have sex with men.<sup>14</sup> In Central and Eastern Europe, injection drug use is driving the spread of HIV.<sup>14</sup> However, trends indicate that as the epidemics in these regions move into the mainstream community, it will be young women who are at highest risk of infection.

## Global Actions

At the United Nations Special Session on HIV/AIDS in 2001, governments from around the globe agreed upon goals and strategies to address the needs of children orphaned and made vulnerable by HIV/AIDS. These strategies include:

- Strengthening the capacity of families to care for children by prolonging the lives of parents and providing families with economic and other support.
- Supporting local community actions to help children.
- Ensuring that children receive essential services such as health care, education, nutrition, and psychosocial support.
- Ensuring that governments develop policies and laws that protect vulnerable children.
- Raising awareness within societies to support children and families affected by HIV/AIDS.<sup>13</sup>

Every child's situation is unique. Interventions will be most successful when children's gender and sociocultural environment are taken into account. Actions on behalf of orphans and vulnerable children must be guided by child-focused principles. Any action should be in the best interest of the child and be non-discriminatory. The child's view should be taken into account, and the child should be encouraged to be an active participant in the process.

## Adolescents

The world's adolescents represent an important population that deserves special attention. As antiretroviral treatment becomes more widely available, HIV-infected children are growing up into young adults. This transition brings critical decisions

and turning points for which proper guidance is often needed.

## Disclosure

Adolescents deal with disclosure issues on multiple levels, including finding out their parents are HIV-positive, finding out they themselves are HIV-positive, and deciding to disclose their HIV-positive status to others. Parents who wait to disclose their own HIV-positive status until their children are teens often experience negative consequences; teenagers in such situations report more risky behaviors and negative effects on family relationships.<sup>15</sup> Regarding adolescents' own HIV status, the American Academy of Pediatrics states that adolescents should know their diagnosis in all cases. That way teens are fully informed of their health status and can make informed decisions regarding their actions and life choices.<sup>7</sup>

Youth living with HIV (YLH) also face the decision of whom else to tell about their diagnosis. Studies show that a majority of youth have disclosed to their families, and many have disclosed to close friends.<sup>16</sup> Disclosing to others is associated with positive outcomes. However, stigma surrounding HIV/AIDS makes people more cautious about disclosure. As a form of stigma management, YLH often are selective about when and whom they tell. They thus protect themselves against negative reactions and social isolation. Teens who are able to find a good circle of support, including people who are aware and accepting of their diagnosis, have greater self-esteem and more positive outcomes.

Once HIV-positive youth begin sexual activity, they enter a realm where they have responsibilities toward their sexual partners. Whether it should be mandatory for HIV-positive people to disclose their status to sexual partners is widely debated. No matter what the law requires, partners need to have the confidence and trust to disclose their status. Some youth do not disclose to sexual partners, especially in casual sexual encounters. But many youth feel a moral obligation to disclose their HIV status so their partners are aware of

the risk of transmission. YLH should be supported through these decisions and provided with alternatives to direct disclosure. For example, if a program to anonymously notify sexual partners exists in the area, it can be used in these situations. Disclosing disease status can be very stressful, especially if the HIV-positive adolescents have deep feelings for their partners and are fearful of rejection. Strong support is needed at this time and should be offered before, during, and after disclosure. This support should be offered to the partner as well.

### Medical Independence

For adolescents living with a chronic illness, the beginning of the transition to adulthood brings an important shift to medical independence. For vertically infected orphans who may have been in charge of their own health care for years, this transition may still require a change in providers or settings, from pediatric to adult health care. For youth who were infected horizontally and had no prior health conditions, health care may be a new arena. Either way, YLH need assistance in taking charge of their medical care.

Tasks they must learn to handle include managing their medications, scheduling their appointments, and discussing their health concerns directly with their health care providers. To perform many of these tasks, teens must understand their condition and feel comfortable discussing it with their health care providers. HIV education will help them feel more confident in these discussions. Some youth will feel unsure as

to which health information is important to share with their providers. To assist them, a health-history summary can document the pertinent aspects of their medical past and help them make a more positive transition.<sup>17</sup> Health-history forms should include a list of medications (past and present), prior surgeries, laboratory work, and any recurrent or major illnesses. For teens who are switching to a new provider, additional support is needed to ensure a smooth transition. For example, someone from the pediatric office might accompany adolescents to their first few visits with their new providers.

### Self-Esteem and Identity

The adolescent years are a time when identity is developed and children decide what kind of person they wish to be, one of the most important developmental stages prior to adulthood. Healthy youth pass through three stages during this transition. Early adolescence focuses on a shift in attachments, from parents to peer groups. During middle adolescence, youth work on their self-image and begin to develop



*Young people with HIV need psychosocial support as well as medication.*

abstract reasoning. Late adolescence is when youth begin to feel comfortable with who they are becoming. They also gain awareness of others and their relationships.<sup>18</sup> Adolescents with HIV/AIDS may have difficulty passing through these three stages.

If the disease is fairly advanced, the youth may have a delay in physical development, including a delay in pubescent changes. Consequently, HIV-positive youth may appear younger and smaller than other adolescents because they have not begun the physical process of becoming adults. They may also experience physical changes as a result of their illness, including wasting and opportunistic infections that may cause noticeable physical symptoms. If youth feel different from their peers, they have a harder time bonding with them. This has an adverse effect on these adolescents' attachments, making it difficult for them to separate from their parents. These changes may also contribute to a negative sense of self-image for these adolescents. They may feel unable to identify with their peers or singled out from other teens due to stigma.

Adolescence is also a time of exploration. Exploring who they are helps youth in their identity development. The stress of having a chronic illness may prevent some YLH from wanting to participate in psychological exploration. This is especially true if they are in denial or are having trouble accepting their HIV status.<sup>19</sup> Developing an identity is a difficult task for any young person, a task that requires guidance and support. This is especially true of young people living with HIV.

## **Sexuality**

Sexuality is an important topic for adolescents, who are at the age when sexual exploration begins. Their drive to explore their sexuality makes adolescents a pivotal population in the HIV/AIDS epidemic. Many youth are poorly educated about sex. This lack of education and the likelihood that they will not practice safer sex leaves teens at high risk of contracting and

transmitting HIV. Youth are also engaging in sexual exploration at younger ages than in the past. This is of great concern, because younger groups are even less likely to be educated about sexual protection.

A study conducted in 1999 showed that if youth perceived themselves as more mature than their chronological age, they were more likely to engage in sex earlier than their peers.<sup>20</sup> Their desire to transition into adulthood also was a major factor in their remaining sexually active after their first sexual encounter.<sup>20</sup> This is important in the discussion of HIV-positive youth because of the increasing number of families headed by young adults. With the absence of parental figures, often due to AIDS, youth are being placed in caregiver roles at much younger ages. Many care for younger siblings, and some are sole providers for their families. With these responsibilities, youth may feel greater autonomy and may wish to participate in other adult behaviors besides caretaking, such as sexual intercourse.

An important group within the adolescent population is the non-heterosexual youth, i.e. homosexual and bisexual youth. These youth face the additional stressor of "coming out" to their friends and family about their sexual orientation. This is a daunting task, given the large amount of public stigma and discrimination toward homosexuals and bisexuals. These teens feel different from their peers and experience the "gay-related stress" of growing up homosexual or bisexual in a hostile environment. Symptoms of gay-related stress can include anxiety about disclosing they are gay and fears that someone will inadvertently find out about their sexual orientation.<sup>21</sup>

These youth must learn to integrate their homosexuality into their greater identity. This is a difficult process if their home environment is not accepting of their sexual orientation. Stress increases if the teen is HIV-positive because of the additional stigma carried by the disease. Young homosexual men are at increased risk of becoming infected with HIV

and of transmitting the disease. This makes homosexual youth an important population to reach with HIV education and support. Only education and support will help them achieve positive psychological outcomes and provide them with the tools to protect themselves and others.

### **Risky Behaviors**

Many youth, regardless of HIV status, engage in risky behaviors during their adolescent years. The most common risky behaviors include unprotected sexual intercourse and the use of illegal substances. Many youth engage in unprotected sex even if they are aware of their HIV-positive status. This puts them at risk of contracting sexually transmitted infections, including reinfection with different strains of HIV. Unprotected sexual intercourse also puts their partners at risk of contracting HIV. Studies have shown that females are more likely to use protection than males.<sup>22</sup> However, in many places females are not in a position of power to protect themselves during sexual intercourse.

Substance use and abuse are common risky behaviors among today's youth. A growing number of young people use tobacco products and consume alcohol on a regular basis. Marijuana is the next-most-popular drug. Tobacco, alcohol, and marijuana are sometimes called "gateway drugs" because of some evidence that they may lead some users to experiment with other drugs. Hard drugs, such as cocaine and heroin, are used less frequently, but their presence in the adolescent scene is growing. Youth who begin using substances early tend to use more substances more frequently as time goes on.<sup>23</sup> Substance use and abuse are serious problems for YLH. These substances can cause a decline in immune-system function, which may strengthen the virus. In teens on HAART, the substances can have adverse effects and interactions

with the medications that can make them very ill. Like many antiretrovirals, many illegal substances are processed through the liver. Combining the two may lengthen the time that illegal substances stay in the bloodstream, increasing toxicity and the chance of overdose. Educating teens on these adverse side effects may guide them to make safer life choices.

Adolescents with HIV must feel supported and gain the education they need to protect their health. This education can and should come from multiple sources, including family, school, church, and community groups. Regardless of their HIV status, youth are at the experimentation stage of their development. But the manner in which they experiment can be protective of themselves and all others.

### **Conclusion**

Education and support are the tools that help children and adolescents with HIV survive into psychologically healthy adulthood. Support can help children recover from the devastating loss of parents and loved ones. With proper support, children with HIV/AIDS can progress through the appropriate developmental stages and grow alongside their peers. Through education, children and adolescents can learn to care for themselves and protect themselves and those around them. They can also extend this education a step to educate others and help reduce the stigma that still makes life harder than necessary for many people with HIV. Through the many changes and challenges of childhood and adolescence, the support of family, friends, communities, and health care professionals is essential to the well-being of tomorrow's adults.

## Review Questions

1. What are stages that families dealing with chronic illness pass through?
2. What is stigma management, and what are some examples of its use?
3. Why are young women at increased risk of HIV infection?
4. How does a 3- to 5-year-old child understand death?
5. Name some ways to assist adolescents in their transition from pediatric to adult health care.

## Exam Questions

1. Internalized stigma occurs when:
  - a. A person sees stigma in others
  - b. A person believes society's negativity about his or her disease or status
  - c. A person chooses to associate with something that is stigmatized
  - d. None of the above
2. Challenges involved in living with chronic illness are:
  - a. Behavioral
  - b. Emotional
  - c. Cognitive
  - d. All of the above
3. Care for grieving children should include:
  - a. Discussions at their developmental level
  - b. Made-up stories of what happened to their dead loved ones
  - c. Support as they fulfill their roles in grieving rituals
  - d. a and c

*Answers: 1b, 2d, 3d*

## Case Studies

### Case Study #1

Thomas is an 18-year-old with HIV infection. He has been coming to your pediatric practice for many years. Now he must transfer to an adult clinic for financial reasons. Thomas is nervous about his transition and has come to you for help.

#### Questions:

1. How can you help Thomas feel more comfortable in this transition?
2. If you use a health-history summary, what should it include?
3. What can be included in Thomas' education regarding his condition?

**Answers:** Thomas is going through a transition that is common among teenagers. There are a few things that can be done to assist him. First, a worker from the pediatric office can accompany Thomas on his first visits with his new provider to make him feel more comfortable. Second, role-playing can help Thomas practice questions to ask his new provider. Third, a health-history summary can help smooth Thomas' transition. This summary should list medications (past and present), prior surgeries, lab work, and any major or recurrent illnesses. Thomas also needs to be educated about his health status. If he has previously been educated about his HIV, this is a good opportunity to refresh his knowledge. Things that can be discussed include the types of lab tests performed and what they look for, how his medications affect his body and how they impact the virus, possible side effects of his medications, and how he can protect himself and others with universal precautions. (For further details, see the section on adolescents' medical independence above.)

### Case Study #2

Emily is a 6-year-old HIV-positive girl who is developmentally appropriate for her age. Her father

died three days ago, and her mother has been gone for several years. Emily will be staying with her paternal grandparents, but they have no room for her younger sister, who will have to live elsewhere. Emily is unsure about what happened to her father, and her family has avoided speaking with her directly about his death.

#### Questions:

1. At the age of 6, what does Emily understand about death?
2. What are some additional stressors Emily is experiencing that could be compounding the loss of her father?
3. What are some things you would discuss with Emily's grandparents now that they have custody?

**Answers:** Developmentally, Emily is at the beginning stages of comprehending death. At the age of 6, she is probably curious about what has happened to her father and where he has gone. She may believe that her father is simply in a different location and will return sometime in the future. In Emily's mind, her father is still alive and functioning – just somewhere away from her. She is also experiencing other losses that may be compounding the loss of her father. Emily's mother has already died, so she now has no living parents. Emily is moving away from her home to live in a different environment with her paternal grandparents. She is also about to be separated from her younger sister. Although Emily may be too young to understand death in the absolute sense, she needs to be talked to regarding her father's passing. Her family has avoided discussing his death with her, and this could add to Emily's confusion and sense of loss. Emily may also begin to sense a feeling of secrecy within the family, which may prevent her from asking her grandparents questions. Now that Emily's grandparents are caring for her full time, it is important to make sure they

understand all that is involved in her care. They should be educated about HIV, including routes of transmission, the importance of clinic visits and medications, laboratory work and what the lab results mean, and how HIV will affect their daily care of Emily. They should be supported through this process and should be allowed to ask questions. The grandparents should be assured that they are not alone in this situation and that they can expect support from the clinic staff. (Please see the section on death and bereavement on Page 298 for further details.)

### Case Study #3

Constance is a 15-year-old living with HIV. Her mother died two years ago, and Constance has been caring for her two younger siblings since then. She has conveyed to you that she has been having sexual intercourse for the past three months. Constance says she is in love with her partner but is unsure of his faithfulness. Constance reports that she and her partner always use condoms, but lately he has been asking for sex without them. She has not disclosed her status to him for fear he will reject her.

#### Questions:

1. **What behavior is Constance performing through her non-disclosure?**
2. **What are some stressors that Constance is experiencing in her life?**
3. **In what way would you educate and support Constance?**

**Answers:** Constance is engaging in stigma management by not disclosing her HIV-positive status to her partner. She is limiting whom she tells because she fears negative reactions and rejection. Constance is experiencing multiple stressors in her life. She is probably still dealing with her mother's death two years ago. She is the sole caregiver for two younger siblings, a huge task for a 15-year-old. She is also worried about the faithfulness of her partner and is dealing with pressure from him to have sex without a condom. Constance is living with the secret of her HIV status. She needs support and education during this time in her life. A clinic worker who has a close relationship with Constance should have an informal one-on-one counseling session with her regarding her reasons for not disclosing her HIV status. Invite Constance to bring her boyfriend to the clinic and to disclose her status with clinic staff present. That way the staff can provide support to Constance and help answer the boyfriend's questions and provide him with thorough explanations about HIV. Also give Constance a chance to role-play with someone at the clinic how she would like to disclose to her boyfriend. This will allow her to practice what she wants to say during her disclosure. There are a number of other things that can be done, and each will be specific to the individual situation. However, in each situation, be sure to provide as much support and education to the adolescent as possible.

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