Psychosocial Aspects of HIV/AIDS:

Children and Adolescents

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Objectives

1. Identify psychosocial factors that affect children and adolescents infected with human immunodeficiency virus (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 of HIV status.

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 infected with and affected by HIV/AIDS.

Key Points

1. Pediatric patients with HIV/AIDS experience 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 of HIV status.

3. Death and bereavement are important aspects of chronic illness that must be addressed with children and their families.

4. Orphans and young girls are at increased risk of contracting sexually transmitted infections, including HIV, and of receiving less support and education than their peers.

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

Overview

Children and adolescents are an ever-growing part of the human immunodeficiency virus (HIV)/AIDS pandemic. In 2007, an estimated 2.1 million children younger than 15 years were living with HIV, and 290,000 children died from the disease in 2007 alone. 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 pandemic is just as significant. The psychological and social effects of HIV/AIDS are magnified in today’s youth.

Children involved in the pandemic 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 important aspects of the HIV/AIDS pandemic, including stigma, disclosure, and death, as well as how health care professionals can support them while dealing with these challenges.

HIV/AIDS as a Chronic Illness

In many parts of the world, HIV/AIDS is still viewed solely as a terminal illness, a disease from which there is no recovery. However, 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 is a disorder with a protracted course that can be progressive and fatal or associated with a relatively normal life span despite impaired mental and/or physical functioning. This broad definition encompasses multiple types of conditions, ranging from fatal to lifelong, including HIV/AIDS. Unlike acute conditions, which develop and resolve within a limited amount of time, chronic conditions are permanent and usually have no cure. Of the main characteristics experienced by children with chronic conditions, children with HIV infection may experience the following:

• 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

Because chronic illness persists for an extended time, infected children and their caregivers go through psychosocial stages that can be sources of great stress, including the following:

• Initial diagnosis

• Disclosure of disease status to the child

• Difficulties resulting from long-term care, including financial and emotional strain

• Preparation for and acceptance of the patient’s eventual death

For pediatric patients with HIV, the preceding stages have increased psychological stress. Stigma surrounding HIV negatively affects disclosure, influences daily care of the patient, and even continues through to the patient’s death. With regard to difficulties with long-term care, adherence to HIV medication regimens is extremely taxing on the patient and his or her family. To prevent resistance, the child must take the medications with a greater than 95% rate of adherence. This task can be difficult for an adult patient and increasingly difficult when the patient is a child or adolescent. Oftentimes, caregivers fall into the pattern of “miscarried helping.” In miscarried helping the family feels the overwhelming need to help the patient with his or her medication regimen and becomes excessive in the frequency of their helping. They may also invoke negative feelings in the patient by telling him that he is “bad” when he misses his pills. As the patient gets older, he wants to have a sense of autonomy from his caregivers. With the family’s need to help and the patient’s need for autonomy, conflict arises, which can lead to poor health outcomes for the patient. Health care providers must guide the caregiver to ask the patient how to best be helpful regarding medication adherence. By giving the patient the power to direct the help from their caregivers, the patient feels a sense of control over the helping while the family can remain involved in the care.

The stressors of a chronic illness can be more challenging when the patient is a child. This situation increases the necessity for caregivers and other family members to assist with medical care and 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 accept the child’s diagnosis. Doing so includes grieving the loss of the idea of their once-healthy child, as well as guilt, sadness, and anger. If the child acquired HIV through mother-to-child transmission, the mother may feel enormous guilt and may be blamed by other family members for the child’s infection.

The cognitive challenge is to educate the child’s family about HIV/AIDS. They must understand the available treatment options and 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 when the child falls ill or develops new symptoms. The cognitive challenge also includes education specifically for the patient. The pediatric patient must have a developmentally appropriate understanding of why they see the doctor and why they take medications. This understanding may include using developmentally appropriate language such as “bugs” in place of HIV or “soldier cells” in place of CD4/T cells. Often, education with children is more successful with visual tools such as drawing and videos.

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

Living with a chronic illness can lead to psychological stress that can build over a long time. People living with HIV are twice as likely to be diagnosed with major depressive disorder. Children living with HIV may have decreased social functioning in comparison with their peers. This decline in social functioning or peer relations may signify the child’s increased difficulty managing his or her HIV diagnosis and/or treatment regimen. This decline may be more apparent as the child grows older and the significance of his or her HIV infection changes with relation to developmental stage. Also, living with a long-term chronic condition also lends a patient to experience burnout. With burnout, a patient may feel depressed and isolated. He or she is frustrated with the medication regimen and the constant requirement to maintain greater than 95% adherence. Often families will shame or guilt their children into taking their medications consistently, which will wear down the patient mentally over time. Health care providers can help reduce patient burnout in chronic illness by using “the 4 Rs”:

1. Realistic goals

2. Reduce blame and criticism in medication adherence

3. Reach for progress, not perfection

4. Recognize negative feelings about disease management as normal and important for the patient to discuss

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 that these challenges can have on the children and their caregivers. With proper support from their health care providers and their community, the challenges of living with childhood HIV/AIDS will be easier to surmount.

HIV/AIDS and Stigma

A major distinction between HIV/AIDS and other chronic or terminal illnesses is the stigma associated with the disease. This stigma often stems 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.

Previous work has defined *stigma* 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.” The stigma that a person carries can alter how he or she perceives and interacts with the world, even affecting how a person thinks and feels about him- or herself as an individual. Stigma surrounding HIV/AIDS is not particular to one generation or one part of the world. It has been an evolving aspect of the disease since the first cases emerged in the early 1980s, and it has become prevalent in all geographic locations—even those with limited mass media influence.

The stigma surrounding HIV/AIDS originated with the association of the disease with homosexual men and intravenous drug users, two marginalized groups in which HIV/AIDS first gained medical attention. The mass media played a large role in increasing the level of stigma around HIV/AIDS. When the medical community initially thought that HIV was transmitted solely among homosexual men, the media came to refer to HIV as “the gay plague.” Through this language, people generalized HIV to be associated with perceived immoral behaviors such as sexual promiscuity and intravenous drug use. Although the medical community soon discovered that transmission was not limited to these groups and behaviors, stigma persisted. HIV/AIDS stigma is also reinforced by the fact that the disease can be fatal, has no cure, and has noticeable physical effects during its advanced stages.

The pediatric population was not a prominent part of the media attention in the initial phase of the pandemic. When HIV/AIDS was first being documented, few children were known to be 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 nearly all HIV-positive patients younger than 15 years. Infection among adolescents (aged 15-24 years) is growing at an astounding rate, mostly through sexual transmission.

Three concepts are helpful in understanding stigma as it relates to the pediatric HIV population: associative stigma, internalized stigma, and stigma management.

Stigma is associative when it affects people because of their association with a stigmatized person, such as a person living with HIV. Associative stigma may affect caregivers who help care for infected children or affected children whose parents have died from the disease. Children may be affected by associative stigma if their parents are publicly known to be infected with HIV. Other examples include being friends with an HIV-positive person and attending a social or fundraising event aimed at people living with HIV.

Internalized stigma can be particularly damaging. Such stigma occurs when a person is aware of a social stigma and accepts, or internalizes, society’s negative views. Doing so damages the person’s self-esteem and gives him or her a negative sense of self-worth. Internalized stigma has a large effect on the pediatric population through its influence on parents’ decisions to disclose. 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. Adolescents may fear disclosing their status to others and feel shameful regarding their condition.

Stigma management is a way of coping with stigma by being aware of possible negative reactions and finding ways to minimize them. People living with HIV practice stigma management by choosing and limiting whom they disclose to in order to minimize the chance of negative reactions or rejection. They may also “test” potential friends or loved ones they wish to disclose to by discussing HIV education or using probing questions to discern the person’s understanding and personal opinions regarding people living with HIV.

Stigma surrounding HIV/AIDS can severely influence those infected with or affected by the virus. Many people living with HIV fear the stigma from their community more than they fear dying from the disease. Prone to both stigma internalization and stigma management, HIV-positive people are less likely to seek social support for fear of rejection and isolation. In some areas, because of stigma HIV-positive children are banned from school and other community activities. In other regions, children are allowed to attend school but are required by law to reveal their HIV status.

To safeguard a child from experiencing stigma, caregivers often practice stigma management and delay disclosing the child’s diagnosis to the child. Between 25% and 90% of school-aged HIV-positive children are unaware of their own HIV status. Some caregivers feel that if children are unaware of their diagnosis, they are less likely to tell the wrong people. Other caregivers feel that if children know their diagnosis, they will internalize the stigma and give up hope. In this way, stigma leads to an atmosphere of secrecy within the family that the child often senses. Children become acutely aware of parents’ feelings toward their diagnosis, through observing interactions with other adults and how they discuss, or avoid, the topic in their presence. Labeling the diagnosis as a secret that cannot be discussed serves only to increase the stigma. Many parents are also afraid to disclose the child’s HIV-positive status because of deep feelings of guilt or shame. The parents may feel guilty about their role in infecting the child and fear that the child will become angry or blame them. Caregivers fear that disclosure of HIV status will eventually lead to questions related to modes of transmission for the adult, which may involve discussing family secrets such as infidelity or drug use.

Clinicians play a large role in assisting families with the disclosure process. Many families choose to disclose in the clinic setting so that they can receive the educational support of the physicians and other clinic staff. Disclosure is not one event but rather more of a process. The patient should be allowed to absorb the information at a pace that is comfortable, which often means that the discussion may start during one visit and continue through the next few visits. It is good to begin with universal terms that children and youth will understand, such as describing CD4 cells as “soldiers” and HIV as a “bug.” It is beneficial to use as many audio and visual aids as possible because many children learn better with these additional tools. If medications are available, discuss the diagnosis as a chronic illness and provide the patient with realistic hope. Because many disclosures take place in the clinic setting, it is important to ensure that clinic staff are trained and comfortable in participating in the disclosure process. Caregivers should also be prepared for disclosure: the caregiver may be asked additional questions when the family has returned home and the child begins mentally processing the disclosure.

Patient families need to be supported and educated, along with their communities. Through basic education about the virus, how it is transmitted, and treatment options, much of the stigma surrounding HIV/AIDS 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 educating the community at large, families and children infected with and affected by HIV/AIDS can receive much-needed support and will no longer feel alone in their struggle.

Death and Bereavement

Despite the increased availability of highly active antiretroviral therapy, many people lose their lives to HIV/AIDS each year. In addition to the children who die from HIV infection, millions of affected children lose one or both parents to AIDS. Often children’s psychosocial needs are overlooked during this time of loss, and children are not given full recognition or support. This problem is usually due to the belief that children are too young to understand what is happening or are better served not dwelling on their grief.

It is often difficult for medical professionals to work with dying patients. Medical training often does not address how to provide palliative care, and many of the lessons learned around dying are done informally and at the time of the patient’s death. Physicians often do not feel comfortable addressing death with patients for fear that the patient will lose hope and give up. It is important to have open and honest discussions with patients to help increase their understanding of the situation and feel supported by their medical team. In a study completed in Uganda, the three most important needs of the dying patient were control of pain and symptoms, counseling services around stigma and healing family relationships, and addressing financial needs for surviving family members. The preferred site of care in the end of life was at home. At home, a patient feels that he or she can better maintain privacy and can receive support from family and sometimes the larger community. Often, patients are most afraid of dying alone, and being able to spend their last days at home can calm this fear.

When a parent or caregiver approaches the end stages of AIDS, a plan of care must be created for the surviving children. This process 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, which 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. Children whose parents do not complete permanency planning are at increased risk of developing emotional and behavioral problems. Several things should be considered when creating a permanency plan. It is best to start with the needs expressed by the dying caregiver. Ask open-ended questions, such as “What do you feel are the most important issues for your family after you pass?” and “What will be left undone if you were to die sooner rather than later?” The caregiver should decide where the children will live once he or she has passed. This could be in the home with the surviving parent or with another family member. It is common if the surviving parent is the father to have the caring shifted to a female relative, potentially outside the home. Conversations with the person chosen to be the future caregiver should take place to make this person fully aware of this new responsibility and to ensure acceptance of the plan. If possible, financial planning should be discussed to help pay for food, clothing, and school fees if needed. For surviving children with medical conditions, education sessions should be conducted with the new caregivers prior to the parent’s passing. If possible, have the new caregiver attend a clinic visit with the parent and child. This way the new caregiver can become familiar with the setting and the clinic staff and can ask questions about the illness and/or required medications. Having a permanency plan in place will help ease the transition after the caregiver’s death.

For children who have lost parents or family members, grief can be overwhelming and hard to understand. The death of a parent is one of the most stressful life events that a child can experience. The effects of this loss can be found years after the death occurs, often not even manifesting until 1-2 years later. Some children even show symptoms of posttraumatic stress disorder after the loss of a parent. This disorder is more common in girls, children who are on average younger, and children who still live with a surviving parent. Losing a parent, particularly at a younger age, demonstrates early for a child that he or she is not invincible and brings into question his or her own mortality. This effect can then be compounded if the parent died from AIDS-related illness and the surviving child is HIV positive.

Grief and bereavement experiences are unique to each individual and often involve different types of responses, including physical, emotional, behavioral, cognitive, spiritual, and social. Grieving children must be able to discuss and acknowledge their loss and must have an opportunity to release their grief. For example, children could write letters addressed to the person they lost. Doing so gives them the opportunity to say feelings or thoughts that were not relayed prior to the person’s passing. Younger children might draw pictures instead of writing letters. Without such opportunities to release their grief, they may experience psychological ramifications well into adulthood.

Children commonly experience a regression in their behavior while grieving. They may begin to display behaviors that they have not exhibited in a long time. Some examples are wetting the bed, self-soothing actions such as sucking on their thumbs, or increasing their physical contact with adults—all actions that help increase their sense of security in a time of confusion. Attention helps children to remember that they have not been forgotten. Some children will try to gain attention through acting-out behaviors. Although acting-out behaviors often result in negative responses, children will ultimately be reassured by the one-on-one attention that they get through discipline from an adult.

One must understand how children’s views of death are shaped by their developmental age. For children younger than 4 years, comprehension of death is limited. Their limited language skills at this point in their development also affect this issue. The children recognize a change in their patterns of care and realize that the deceased person is no longer in the environment. These children may be more irritable than usual and may exhibit regressive behaviors. Maintaining consistency within the home and providing constant reassurance are both ways to help young children cope with the loss and change to their environment.

From 4 to 7 years of age, children believe that the deceased parent is just away for a short time and will eventually return. For them, death is something that is reversible. They have no comprehension of the finality of death. They may ask questions regarding the process of death and be curious regarding the “how” and the “why” of the person’s passing. The child may attempt to do tasks that were originally the responsibility of the deceased. Children of this age also begin to exhibit forms of “magical thinking,” in which they believe that 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 that he is responsible for her death. Children in this age range should be allowed to discuss the loss and to ask questions in a supportive environment.

At ages 7-11 years, children come to realize that death is final and irreversible. These children are concrete thinkers and have trouble comprehending anything beyond the physical death that has occurred. They may not understand why the person passed away and will ask detailed questions. Through experiencing the death of a loved one, the children in this age range worry about their own bodies and any bodily harm that could be done to them. They may also be concerned regarding how others are responding to the death. During this period, children may show aggressive tendencies, display risky behaviors, become excessively impulsive, and might also regress. It is important to be open and allow discussion if the child is interested; however, it is also important to allow the child to process his or her thoughts alone if needed.

During adolescence, ages 11-18 years, youths begin to understand death in an abstract sense. They think of death in terms of an afterlife as well as a physical death and try to make logical sense of death within the larger framework of life. As adolescents are developmentally separating from family and aligning with peer groups, they may often want to gain support from friends outside family relationships. Adolescents might experience random and intense emotional outbursts. Adolescents should be provided with opportunities to verbalize their grief and should have their feelings validated during this time, not minimized.

It may take years for a child or adolescent to fully accept a parent’s death. Support is a key factor in grieving. 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. For some, participating in rituals can help with the transitional period caused by the loss and help begin acceptance of the loved one’s passing. For others, these roles can increase the trauma experienced by the mourner. Children must be supported before and after the ritual to reduce the amount of stress that they experience. If participation in the ritual is optional, children should be allowed to choose whether they would like to participate.

The concepts of death and dying become more complicated when the dying patient is a child. When facing their own death, many experience anticipatory grief. With anticipatory grief, the dying person is still alive, but the patient and family members begin grieving prior to the death. Often, people experiencing anticipatory grief will project their feelings onto others. For example, children who are dying may be more afraid of their caregivers’ dying. They will panic at the thought of anything traumatic happening to their caregivers, when in fact they are afraid of their own death and what will happen to their loved ones when they are gone. Children may also show signs of knowing about their fate through symbolic play or art. They may pretend that toys are dead or draw death in their artwork. Children may become withdrawn, quiet, increasingly irritable, and display regressive behaviors. They will inevitably feel a loss of control in the world around them. To help children face this oncoming event, they must have 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 that the child will understand, and the answers should be honest. Children should be allowed to participate in decisions affecting their care at the end of life. They are the best resource for determining what they want and how much they can tolerate in the end stages of their disease.

Unfortunately, death and grief are harsh realities in the HIV 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

The HIV pandemic has increased the risk of children and youth suffering from poverty, illness, and abuse, in essence increasing the preexisting vulnerability of children. Vulnerability can be described in different forms and is affected by the age of the child. Children younger than 2 years are more at risk of parental neglect because of their dependence on adult caregivers. They suffer from lack of food, shelter, and basic care needs if an adult caregiver does not provide for them. Between the ages of 3 and 10 years, children suffer increasingly from lack of educational opportunities, lack of available food, and an increased risk of losing a parent. Adolescents, aged 11-17 years, are made vulnerable by the poverty that surrounds and influences their family. They may be forced to work in jobs that exploit child labor, be forced into early marriages, or have to care for younger siblings. Two specific populations that are more heavily affected by the AIDS pandemic are orphans and young girls.

Approximately 15.2 million children younger than 18 years have lost one or both parents to AIDS, most of them living in sub-Saharan Africa. AIDS has also caused children to lose their siblings, friends, relatives, teachers, doctors, and other significant people in their lives. Also, the mortality rate for children who have HIV-positive mothers is significantly higher than those children with mothers who are HIV negative, showing that children are at a higher risk of losing their own life if their caregiver is HIV positive.

Children orphaned by AIDS are more likely to suffer economic hardship, including loss of property and inheritance. When the family loses a primary caregiver who provided economically for the family, the effects can be widespread. The family may be forced to move to a different region to help earn additional income. For some, doing so includes leaving the rural area to move to the city for more job opportunities or relocating to live with other relatives. Some orphans may not have family members to stay with after a parent’s death. These orphans may try to survive living on the streets or may be forced to stay in an orphanage or institution. Institutions often fail to provide adequately for the physical and psychosocial needs of children, and they actually cost more than direct monetary assistance to families that foster orphans. In some cultures, children will lose property or inheritance when the relatives of the deceased come to claim items such as cars, work equipment, or electronics. This process can compound the loss felt by the surviving children in the family. In addition to economic hardship, educational opportunities for orphans are often limited. New caregivers cannot pay school fees, and often orphans have to work to help maintain the family financial stability or care for younger siblings.

Orphans of caregivers who have died from AIDS may also be infected with HIV. The loss of their caregiver may have direct negative effects on their clinical outcomes. Orphans may experience decreased access to medical care with overwhelmed new caregivers who cannot bring all children to a doctor when needed. In Kenya, HIV-positive orphans who were taking antiretroviral treatment were compared with non orphans taking antiretroviral treatment. Overall, the orphan group had similar short-term outcomes to those of the non orphan group. However, the two groups differentiated with their long-term outcomes in terms of weight gain, with the orphan group decreasing significantly in weight gain after 70 weeks. Also, the orphan group tended to be older at treatment initiation. Fortunately, in terms of adherence and CD4 percentage, there were no differences between the orphans and nonorphans.

Psychologically, orphans may begin to express their difficulties prior to their parents’ passing. They have a hard time adjusting to their parents’ illness and inability to care for them in the final stages of the disease. Children who lose their parents often internalize their psychological turmoil and feel the negative effects from the parental death up to 2 years afterward. Often, the new caregiver does not notice the adjustment difficulties of the orphan in the first 6 months because the child may be well behaved with a new caregiver or too traumatized to externalize his or her negative feelings.

Young women are an equally vulnerable population in the HIV/AIDS pandemic. In countries all over the world, young girls are more often employed in the informal economic sector and are often paid less than their male counterparts, even when they are doing more work. In Northern Africa, the Middle East, Latin America, Asia, and sub-Saharan Africa, young women have a harder time finding employment because of poorer educational opportunities and other social constraints. Some of these constraints include restriction from extensive traveling for employment and lack of available jobs for young people overall. Educational opportunities are lacking for young girls. For example, in India more than half of women aged 15-19 years have no primary education. Sub-Saharan Africa also has a dearth of young girls in school. This lack of education for young women has a ripple effect throughout their lives, affecting their ability to make decisions about their future and their ability to obtain and maintain employment. Poverty within the community can have an increased negative effect on young girls in the family because they are then made to perform daily chores for the household that detract from their ability to obtain an education. They may need to fetch water daily from the community well, which takes away from their ability to leave the homestead for education or outside work and often exposes them to opportunities for exploitation.

Worldwide, young women are at greater risk of contracting sexually transmitted infections, including HIV, and often do not have the power or skills to protect themselves. 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 and other sexually transmitted infections from unprotected sex. A study in Uganda found that young women were nine times more likely to contract HIV than young men. Violence, forced prostitution, incest, and rape, including marital rape, all put girls and women at risk. Coercion can be extremely common among young girls who are living in disadvantaged conditions. Coercion can include forced sex, pressure to have sex in exchange for money or gifts, flattery/pestering/threatening from the male, or passive acceptance.

Every child’s situation is unique. Interventions will be most successful when children’s sex and sociocultural environment are taken into account. Early interventions that include community education and support are essential to help prevent orphans and young girls from being kept out of school and tracked into informal employment.

Adolescents

Adolescents are an increasingly important population that deserves special attention. Today’s young adults are becoming infected with HIV at an alarming rate. Also, as antiretroviral treatment becomes more widely available, HIV-infected children are now provided the opportunity to mature into young adults. Adolescence is a transitional period full of critical decisions and turning points for which proper guidance is often needed.

***Disclosure***

Adolescents deal with disclosure issues on multiple levels, from finding out their own HIV-positive status to deciding to disclose their HIV-positive status to others. The American Academy of Pediatrics states that adolescents should know their diagnosis in all cases. Teens should be fully informed of their health status so that they can make informed decisions regarding their actions and life choices. The youth will often need repetitive education around daily living with the virus and how it will mold decisions that they make in their social lives. These decisions involve managing their own health, disclosing to friends and significant others, and sexual choices. While the youth progress through different life stages, they will experience new and different realizations in relation to their diagnosis.

Youth living with HIV (YLH) face the decision of whom they will disclose their diagnosis to. Many youth have disclosed to their families, and many choose to disclose to close friends. Disclosing to others is associated with positive outcomes and lower stress levels. However, stigma surrounding HIV/AIDS makes people more cautious about disclosure. To manage stigma, YLH often are selective about whom they tell and when, protecting themselves against negative reactions and social isolation. Multiple factors must be considered when deciding whom an adolescent will disclose their HIV status to, including how they have adjusted to their own diagnosis, their assessment of their own disclosure skills, and their motivation to proceed with disclosure. Youths must also evaluate the circumstances of the person whom they plan to tell, anticipate what that person’s reaction may be, and determine how well they feel the person will be able to keep the information confidential. Many feel that they simply do not have the skills to disclose with positive outcomes. One study showed that HIV-positive women felt that deciding whom to tell was easy but that how to tell was hard. Clinic staff can role-play different scenarios with patients so that they can practice what they are comfortable saying and how they can also provide education to the recipient. Teens who can find a strong circle of support, including people who are aware of and accepting of their diagnosis, have greater self-esteem and outcomes that are more positive.

Once HIV-positive youth begin sexual activity, they have responsibilities toward their sexual partners. Whether it should be legally mandatory for HIV-positive people to disclose their status to sexual partners is widely debated. Despite what the law mandates, adolescents need to have feelings of confidence and trust to disclose their status to their sexual partners. Some do not disclose to sexual partners, especially during casual sexual encounters. But many youth feel a moral obligation to disclose their HIV status so that their partners are aware of the risk of transmission. YLH should be supported through these decisions and provided with opportunities to practice disclosure and learn explanations that they are most comfortable using. Disclosing disease status can be stressful, especially if the HIV-positive adolescents have deep feelings for their partners and are fearful of rejection. Adolescents feel a strong need to be similar to their peers and feel accepted. For many adolescents, the fear of rejection can even be stronger than their fear of potentially infecting their sexual partner. Strong support is needed at this time and should be offered before, during, and after disclosure. Offer to have the adolescent bring his or her partner to the clinic if the patient would like additional medical education and support.

***Medical Independence***

For adolescents living with a chronic illness, transitioning into adulthood includes an important shift toward medical independence. Despite their previous experience, or lack thereof, with the medical system, YLH need assistance in taking charge of their medical care. Health service involvement decreases in adolescence at the same time that family involvement in youth’s health care also declines. This situation can have serious negative implications for the youth’s future health as he or she may make poor health decisions, such as missing antiretroviral doses frequently, and are not supported by family members.

Youth should feel empowered to take over their medical care, which requires the clinic staff to use a different approach: involving the YLH in their own goal setting. The youth can no longer be passive in their health care decisions, and physicians must learn to share control over medical decisions with the youth themselves. To help provide this feeling of empowerment, providers must teach adolescents to manage specific tasks, such as 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 first be thoroughly educated on HIV and feel comfortable discussing it with the health care team. With increased HIV education, YLH will feel more confident in discussions regarding their own health care and will be able to make informed decisions about treatment and management.

Often, adolescents may need to transition to a new health care provider/clinic as they age. Many pediatric clinics do not have funding or capacity to keep youth as they age into adulthood. However, many YLH do not feel equipped to leave the clinic where they have managed most of their health care. Many youth feel that the clinic staff are the “keepers of their health history” and do not try to remember specific aspects of their medical care because they know that the staff keep it on record. When meeting with a new provider, some youth may feel unsure regarding which components of their health history are important to share with these new 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. Health history summary forms should include a list of medications (past and present), prior surgeries, laboratory work, any recurrent or major illnesses, as well as establish what the youth may have a family history of—for example, cancers or high blood pressure. For teens who are switching to a new provider, additional support is often needed to ensure a smooth transition. To assist YLH with the transition, a member of the pediatric office staff can accompany them to their first visit with their new provider or go with them on a tour of the new clinic and meet the staff prior to the first visit. It is beneficial to have a strong working relationship with the adult clinic/provider in your area to help ensure a smooth transition and prevent adolescents from falling out of care.

***Self-Esteem and Identity***

The adolescent years are one of the most important developmental stages prior to adulthood. Youth pass through three periods during this transition. Early adolescence focuses on a shift in attachments, from parents and caregivers to peer groups. During middle adolescence, youth work on their self-image and begin to develop abstract reasoning. Late adolescence is when youth begin to feel comfortable with who they are becoming as adult members of the greater society. They also gain awareness of others and their relationships. Youth living with HIV encounter additional challenges while passing through these three stages.

If the disease is untreated, the youth may have a delay in physical development, including pubescent changes. Consequently, HIV-positive youth may appear younger and smaller than other adolescents. 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 look different from their peers, they have a harder time bonding with them, adversely affecting the adolescents’ peer attachments and making it difficult for them to separate from their parents. These changes may also contribute to a negative self-image. YLH may feel unable to identify with their peers or feel singled out from others because of stigma. Individuals develop much of their identity, the sense of who they are, on the basis of how they compare to others. This sense of identity comes from actions within a social context and is based on whether their decisions are accepted or rejected by others in the group. Rejection from the group can have a serious negative influence on one’s self-esteem and identity. For instance, adolescents bullied excessively by peers can have low self-esteem and a negative self-image that lasts well into adulthood. Peer relationships have a stronger influence on behaviors during adolescence than in any other period in life, including childhood and adulthood. Conversely, not being accepted into a peer group can have an equally strong effect on adolescents. Peers have a strong influence not only on adolescent social behaviors but also on health-related behaviors. These influences can be negative, such as smoking tobacco, or positive, such as encouraging medication adherence in support groups. Connecting with a peer group allows caregivers and clinic staff to understand their adolescent patients. The gained understanding of peer influences allows health care providers to help benefit YLH via support groups and adherence buddies.

Adolescence is also a time of exploration. The stress of having a chronic illness may prevent some YLH from wanting to participate in psychological exploration—especially if they are in denial or are having trouble accepting their HIV status. Dealing with a chronic illness shapes and molds individual identities by altering the individual’s view of the world. Their diagnosis may affect their views of caregivers, affect the role of medical care, and influence whom they trust with confidential information or have romantic relationships with. If not accepting of their diagnosis, they may experience long periods of self-doubt and may be overly untrusting of the world around them. Developing an identity is a difficult task for any young person, a task that requires guidance and support—especially for young people living with HIV. As youth develop, they will systematically begin to organize their lives around who they feel they are as individuals and how this affects where they fit in the world around them, all of which is influenced by their HIV status. In turn, this perception of their place in society then shapes the personal and professional choices that they make, which belief system they align with, and which culture defines them. This sense of identity often becomes the measure of their worth as a person. If YLH are hindered by fear and denial of status, the ramifications on their perceptions of their place in the world can be hugely damaging.

***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 pandemic. A study done in Uganda found that by age 18 years, 64% of women and 50% of men already reported being sexually experienced. Many youth are poorly educated about sex and safe sex methods. This lack of education on practicing safe sex methods, and the subsequent likelihood that they will not use protection, leaves teens at high risk of contracting and transmitting sexually transmitted infections. Youth are also engaging in sexual exploration at younger ages than in the past. This trend 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. Their premature transition into adulthood also was a major factor in their remaining sexually active after their first sexual encounter. This factor 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-related death, youth are being placed in caregiver roles at much younger ages. Many care for younger siblings, and some are the sole providers for their families. With these responsibilities, youth may feel greater autonomy and may engage in early sexual intercourse.

Some YLH are afraid to engage in sexual activity because of fear of transmission. Sexual expression is part of human nature and normal development. The ability to express oneself sexually and the opportunity to one day be a parent are an innate part of being human. Some YLH experience strong pressure from family members to abstain from sexual activity and even feel pressure to never have their own children. Clinicians involved with youth must educate them on ways to have safe sexual experiences for themselves and their partners, as well as on ways to have their own children without fear of passing on the infection. All teens and adults experience “prevention fatigue.” Similar to medication adherence fatigue, many find it difficult to always use protection. Females are more likely to use protection than males. However, in many places females are not in a position of power to protect themselves during sexual intercourse. Clinicians need to support youth in the ability to use protection consistently.

Receiving support around having a healthy and safe sexual experience can be difficult for some youth. First, some may not seek out safe sex education or tools for fear that their partner may suspect that they are HIV positive. Adolescents developmentally are at a point where they want to be similar to their peer group. However, YLH are aware of distinct differences within themselves that distinguish them from their peers. Youth may go to extra lengths to reduce the differences that they have between themselves and their peers. One example is engaging in sexual practices without protection. Second, education can sometimes be hard to find in a society that feels that sexual activity is against good morals and values. Sexuality in many societies is not openly discussed for fear that youth will then engage in sexual activity too early or because conversations regarding sex are traditionally held privately within families. However, despite these broadly held beliefs, one study found that 82% of 45 television shows most watched by youth contained sexual behavior or talk of sexual behavior. On average there were 11.1 sexual interactions per hour in these shows. However, rarely in these same shows did the characters discuss or refer to methods of sexual protection or the risks of negative outcomes. This situation highlights that even if family members or clinicians do not discuss sexual behaviors, youth are still being exposed to them through the media. Without education and support from adults around them, youth will be guided solely by their peers and the “education” that they receive from the media.

A group that requires special attention within the adolescent population is 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 because of 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 that they are gay, as well as fears that someone will inadvertently find out about their sexual orientation. These youth must learn to integrate their homosexuality into their greater identity. 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, to provide them with the tools to protect themselves and others.

***Illicit Substance Use and Abuse***

Substance use and abuse are common risky behaviors among today’s youth. More young people often use tobacco products and consume alcohol socially. Behind tobacco and alcohol, marijuana is the third most commonly used substance by youth. Tobacco, alcohol, and marijuana are sometimes referred to as “gateway drugs.” People who use any or all of these substances may be more likely to experiment with other, more addictive, drugs. Drugs such as cocaine and heroin are used less frequently, but their presence on the adolescent scene is growing. In Eastern Europe and many parts of Latin America and Asia, injection drug use is a widespread problem that is also fueling the spread of HIV. Youth who begin using substances early tend to use more substances with increased frequency as time goes on.

Screening for substance use among YLH is important; multiple studies have found an increased prevalence of substance abuse-related disorders in this population. Increased substance using can also indicate poor adherence. Substance use can also have major negative medical consequences for YLH. Alcohol consumption can lead to increased susceptibility to opportunistic infections, suppress the immune system, and even compromise the activation of zidovudine (AZT). Most illicit substances can reduce immune system function, which may strengthen the virus. For instance, prolonged exposure to nicotine specifically inhibits T-cell activity. In teens on highly active antiretroviral therapy, these substances can have adverse effects and interactions with the medications, causing the youth to become ill. Like many antiretrovirals, many illegal substances are processed through the liver. Combining the two may lengthen the time that an illegal substance stays in the bloodstream, increasing toxicity and the chance of overdose. Substance use also tends to decrease behavioral inhibitions and increase other risky behaviors. Adolescents under the influence of substances may choose to engage in unprotected sex, putting their sexual partners at risk of contracting HIV.

Clinic staff should ask patients about their substance-using patterns to help provide them education on the negative health effects of the substances, as well as to provide a baseline for their patterns of substance use. These sessions should not be judgmental; such sessions will hinder the youth from fully disclosing their experience of using substances. Teens should also be reassured that their conversation is confidential so that the YLH will not fear repercussions from their caregivers. Educating teens on the adverse effects of substance use and abuse may guide them to make safer life choices.

Conclusion

Education and support are the most effective 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. Proper support will also help children with HIV/AIDS to progress through the appropriate developmental stages and grow alongside their peers. Through education, children and adolescents can learn to take charge of their own medical care and protect themselves and those around them. They can also extend this education to others and help reduce the stigma within their larger communities. 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.

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