Perinatal HIV: Children with HIV Grow Up
Tracey Bush-Parker, LCSW

Historically, the mention of perinatally HIV-infected youth has raised images of babies. In the year 2000, however, the reality is one inhabited by young people who are entering adolescence and have been living with HIV their entire lives.

Perinatally infected youth who have benefited from improved HIV treatment regimens in 1990s and are now entering their teenage years have become a new focus of health care providers’ attention. Many providers did not expect these young people to survive into adolescence and are now seeking to identify and meet the challenges that perinatally infected youth face. This article focuses on the needs of HIV-positive young people who were infected during the epidemic’s earliest years and are now roughly 13 to 18 years old.

As of September 1997, perinatal HIV transmission accounted for 7,310 (1 percent) of the 626,334 AIDS cases reported in the United States. While rates of perinatal transmission have declined as pregnant women have increased their access to and use of antiviral treatments, the actual number of young people with perinatally acquired infection will probably continue to grow: anticipated improvements in medical treatment will prolong life spans and increase the likelihood of young people reaching adolescence.

Working with perinatally infected youth is similar to working with youth with behaviorally acquired HIV infection, but there are also striking differences. Youth infected at birth are more likely to be at an advanced stage of illness and have multiple physical disabilities as a result of their HIV infection. Perinatally infected youth may be more likely to live in kinship or other alternative familial structures because of the loss of a parent, and are more likely to have parents or siblings who are also infected. When parents are present and HIV-infected, young people may find themselves in a “parentified” role in which they must take on responsibilities of caring for themselves and others because of parental illness or substance abuse.

HIV versus Other Chronic Illnesses

Perinatally infected youth also can be compared with youth facing other early onset chronic illnesses. As is true with these other diseases, HIV infection can affect school attendance and performance because of absenteeism for medical visits and the need to take medications during the school day. In addition, various illness-related factors can affect the nature of relationships—particularly with siblings and parents—as well as opportunities for developing peer group relationships, including romantic ones. Both young people with HIV and those with other chronic illnesses also may experience impairment in physical, neurological, or psychological functioning. Aspects of the stigma, mystery, and secrecy related to HIV added to the multi-generational aspect of HIV infection, however, may make coping with and responding to HIV infection distinct from most chronic illnesses.

Another important difference with HIV relates to disclosure of infection status. A young person’s caregivers may be aware of a child’s infection from soon after the child’s birth but may delay disclosing it to the child for several years. How a young person learns about his or her infection can have a significant effect on social and psychological well-being. Optimally, a young person will have learned about his
There was a time when children were among the fastest growing demographic groups at risk for HIV. Seropositive parents faced a 30 percent to 50 percent chance that their children would be HIV-infected as the result of perinatal transmission. Over the past several years, this scenario has improved dramatically as researchers have shown that zidovudine therapy during pregnancy and immediately after delivery cuts the likelihood of transmission to 8 percent. In the United States—but not in poorer countries—perinatal AIDS cases dropped by 67 percent between 1992 and 1997.

At the same time, combination antiviral treatment has ensured that many children born with HIV are living much longer. These children, born when perinatal transmission was a problem of huge proportions, are coming of age. Much HIV-related mental health care for adolescents has emphasized prevention, but it appears that providers will be seeing increasing numbers of young people with HIV who face psychosocial challenges. In this issue of FOCUS, Tracey Bush-Parker looks at some of these challenges and identifies the conflicts that adolescents and their families face as HIV collides with the stormy psychological development of the teenage years.

What seems to be most true about this time is that the dependence that illness may breed in a person with HIV is the worst thing for an adolescent, whose normal development demands an assertion of independence. For teens, illness limits not only choices but also abilities. In addition, the direct relationship between HIV disease and sexuality makes for the most uncomfortable of bedfellows at a time when, whatever a parent’s (and a young person’s) perspective on the expression of teen sexuality, adolescents are confronted by growing and demanding bodies.

The second article in this issue of FOCUS looks at the special situation when parent and child are the same person: the case of youth with HIV who are also young mothers. Sue Ellen Abdalian and Karen Lingard Wright discuss the motivations for pregnancy in young women with HIV, the complications for both these youth and their children, and the rewards that may result from successfully negotiating HIV, pregnancy, and child rearing.

Both of these articles suggest that the task for providers working with youth is not simply to focus on prevention. It is also about helping young people with HIV deal with the most difficult period of psychological development at the same time as they respond to a chronic and life-threatening illness.

or her infection as a result of a well-planned approach by family, medical providers, and mental health clinicians. Many youth, however, report learning about their diagnosis by “figuring it out” on their own or by being “accidentally” told by medical providers.

Families may delay telling a young person about HIV infection for many reasons. Parents may put off disclosure for fear that the child is too young to understand what it means to be infected. In addition, parents may not want to acknowledge to the child that they themselves are infected, or they may fear a child’s reaction. Despite these concerns, it appears that if a young person learns about HIV diagnosis at a relatively early age—perhaps age 8 or 9, when a child is beginning to accept increasing responsibility for self-care—his or her level of coping at later ages increases: early disclosure offers an opportunity to integrate seropositivity with other developmental challenges. Conversely, the task of disclosing a diagnosis becomes increasingly difficult as young people mature. The

experience of one young person offers insight into this process, “They told me just when I was starting to date and felt popular in school. This destroyed my life. If I would have known earlier, maybe I could have coped differently, knowing what my limitations were.”

Developmental Issues and Relationships

Developmentally, adolescence is a time when youth need and crave increasing independence and responsibility, and take risks in the process of achieving these ends. One challenge in working with HIV-infected youth is to help them attain goals of independence when they have been physically, psychologically, and emotionally dependent on both their families and the health care system. It is not uncommon to encounter youth who are “infantilized” emotionally by families that have sought to protect them from society or the challenges of HIV infection. This is particularly true in terms of HIV treatment, but as youth develop, treatment decision making and responsibility for adherence shifts from their parents and

References
Behaviors such as substance use, social withdrawal and isolation, smoking, poor nutrition, and sexual risk-taking may have greater impacts on the health of HIV-infected youth than on others.

HIV-infected youth also face a variety of challenges regarding relationships with peers. For example, young people with HIV may have as friends only other seropositive youth, have a peer group that is developmentally less mature than they are, or have no friendship circle at all. The lack of diversity of each of these situations may prove problematic. The experience of having only other HIV-infected youth as friends, for example, can prevent people from fostering interests outside of their world of HIV infection and interfere with lessons regarding the challenges of peer group selection and rejection that will occur throughout life. Having a less mature peer group—which may happen because of delayed physical development or setbacks in school—can be harmful because it may affect the way a young person confronts issues of sexuality, love, and intimacy. Having no peer group outside the family can prevent a young person from developing communication and negotiation skills. Dating and sexual exploration, interpersonal conflicts, and intimacy are important experiences for adolescents, who need to establish a meaningful guide for sexual behavior and sex-role identification. The decision to engage in sex—a tough decision for any young person—becomes increasingly complicated for young people with HIV. Negative societal views of homosexuality, associations between HIV disease and homosexuality, and ongoing misinformation about HIV disease can hinder a young person from coming to terms with his or her sexuality—whether gay or heterosexual. Young people must also consider the possibility of infecting others, and weigh this possibility against their own desires for sexual intimacy and gratification. The focus on sexuality may be complicated by physical alterations associated with HIV-related medical conditions such as failure to thrive, wasting syndrome, short stature, and recurrent thrush and herpes. These conditions can affect how a person is viewed by his or her peers and can be particularly destructive to self-esteem.

Planning for the future is part of the maturation process, but the unpredictability of HIV infection can interfere with this process or the accomplishment of life goals. Finally, young people may grieve the loss of friends, family, and health. Self-esteem also may be affected by losses related to growth delays, for example, delays in the development of breasts or pubic hair, of voice changes, or of growth spurts—those changes that under normal circumstances would help them fit in with peers.

**Counseling Approaches**

Individual, group, and family counseling approaches all can be useful when working with seropositive youth infected from birth. In individual therapy, youth may benefit from exploring issues such as social isolation, grief and loss, anger at parents about being HIV-infected, sexual decision making, and methods of coping with various challenges. Techniques such as confrontation, reframing, writing a journal, role-playing, and art projects can be useful, but must be employed in the context of each client’s psychological development and with sensitivity to cultural factors. Providers face the ongoing challenge of encouraging healthy sexuality as well as sexual responsibility and decision making. This entails looking at issues of disclosure to sexual partners and issues related to safer and unsafe sex.

In group settings, therapeutic goals include helping youth to gain peer support, enhance psychosocial functioning, reduce depression, and recognize isolation. The facilitator’s role is to develop other's to themselves. Many families struggle with young people’s developmental needs for independence, especially given that adolescents may make decisions different from those their parents would make. For instance, a young person may feel that the immediate discomfort or inconvenience of treatment is too great and may therefore decide against more complex treatments that a parent may see as essential to longer-term survival.

While risk-taking is part of the developmental process for all youth, its consequences can raise particular challenges for young people with HIV. The struggles that arise in navigating difficult life issues, developing intimacy in peer relationships, and dealing with other emotional challenges can result in a particular vulnerability to harmful behaviors. Behaviors such as substance use, social withdrawal and isolation, smoking, poor nutrition, and sexual risk-taking may have greater impacts on the health of HIV-infected youth than on others.

and sustain relationships among clients and with the facilitator. Modeling for clients, the facilitator must instill hope, provide realistic encouragement, and identify ideas that are common among members. Approaches such as role-playing, predetermined discussion questions, and therapeutic board games are useful in establishing relationships and trust. Group activities may include creating a written group history to which every member contributes. If members agree to do so, visiting peers in the hospital or holding groups at alternative sites also can be useful in preparing members for the departure of peers.

In some cases, sustaining long-term client progress may require family therapy. Even if family intervention is ultimately warranted, providers should meet with youth separately and model strategies that help families learn new ways of looking at their child or sibling. Providers should be attuned to the risks families may represent to the client as well as the strengths of the family system.

Providers are likely to have a variety of feelings while working with perinatally infected youth. These feelings may include value judgments about a client’s decisions, especially those related to treatment choices and sexual decision-making, and there is a risk that these feelings will be particularly acute in light of the temptation for providers to "parent" adolescent clients. It is crucial for providers to recognize resistance, transference, and countertransference in these cases.

Two other issues are important to mention: confidentiality and trust, and the process of taking a client’s history. As with any therapeutic relationship, it is essential to review confidentiality laws and provider expectations in the initial session to ensure clients that private information will not be revealed inappropriately. Youth, in particular, need assurances that information they provide will be respected and used only in their best interest, and this assurance is crucial to establishing trust. Many young people have learned that putting trust in the wrong person can create havoc. An inappropriate disclosure of information may cause embarrassment and fear and have the long-term effect of inhibiting a young person from disclosing information in the future when doing so is in his or her best interest.

The process of taking a young seropositive client’s history can raise challenges. Clients may have long health and psychosocial treatment histories, and young people and their families may be frustrated by the need to repeatedly retell these stories. In addition, it may be difficult to assess how a client’s development relates to the normal range of behaviors for adolescents. The HEADSS tool (the acronym stands for home, education, activities, drugs, sex, and suicide) can be useful for this task: it structures questions to maximize communication and minimize stress. Issues that may be key to explore include other chronic illnesses, coping, familial relationships, relationships with health providers, and other factors that may affect development and coping, for example, a parent’s substance-using history.

## Conclusion

Adolescents infected with HIV since birth are a new population in the ever-changing HIV epidemic, and providers have much to learn from these young people. Proper education is necessary in order to work with these youth as they develop physically and emotionally, and to prepare to work with future generations of HIV-infected youth, who will inevitably follow.

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### Authors

Tracey Bush-Parker, LCSW is the Associate Director, Clinical Services at the Los Angeles Family AIDS Network. Previously, she worked at Children’s Hospital Los Angeles as Project Director of School Health Programs and as a Clinical Social Worker in the hospital’s Risk Reduction Program for HIV-infected youth. She has worked with HIV infected youth since 1991, and has served in various professional capacities, including case management, individual, family, and group therapist.

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### Clearinghouse: Youth and HIV

Helping Young Mothers with HIV
Sue Ellen Abdalian, MD and Karen Lingard Wright, MEd

Although teen pregnancy rates in the United States have decreased over the past decade, adolescents are well-represented among HIV-infected women giving birth each year. Adolescent pregnancy alone places young women and their children in jeopardy of disadvantageous outcomes in education, employment, income, family structure, health, and welfare.1 When HIV is present, pregnancy and parenting issues appear to be intensified and more complex.

Psychosocial Development, Planning, and HIV
Adolescence is a time when young women struggle with conflicting needs for autonomy and a desire to belong. Any chronic illness marks a teen as special in a negative way and interferes both with her ability to fit in with her peers and to decrease dependence on her family. Adolescents with HIV must seek to incorporate an especially stigmatizing and life-limiting disease into their identity development.

Cognitive changes during adolescence are gradual. For adolescents whose thinking reflects the concrete patterns of childhood, what cannot be experienced directly cannot be understood. Therefore, when a teen feels healthy, it may be difficult for her to experience HIV infection as a real phenomenon, to fully comprehend the concept of disease transmission, and to understand the need for preventative care and for medications.


References


Contacts
Tracy Bush-Parker, LCSW, Los Angeles Family AIDS Network, 6430 Sunset Boulevard, Suite 1202, Los Angeles, CA 90028, 323-669-5616, traceybush@aol.com (e-mail).
Sue Abdalian, MD, 504-586-3881 1430 Tulane St, New Orleans, LA 70112, 504-948-6701, 504-584-3619 (fax).
Karen Wright, MEd, Children’s Hospital of New Orleans, Family Advocacy Care and Education Services (FACES), 3308 Tulane Avenue, New Orleans, LA 70119, 504-821-4611, kwright8@bellsouth.net (email).

See also references cited in articles in this issue.
es womanhood, and is commonly viewed as healthy. In a study of HIV-infected women with substance abuse histories, subjects identified childbearing as a way to establish independence and to experience deliverance from loneliness, loss, and hopelessness. Young women may seek pregnancy as a way to “leave something behind,” to please their beloved, to get affection, or to express their health and vitality in the face of HIV. Other studies have also found that the expectation that having a baby would create some positive result appeared to play a significant role in the decision to become pregnant.

During pregnancy, the denial of disease normally experienced by other people with HIV can be offset by the simultaneous wish to guard against any possible harm to the developing baby. Pregnancy is the circumstance in response to which most teens, even those who doubt that they are actually infected, will initiate medical treatment early. Others avoid care even during pregnancy to escape the reminder of HIV. As is true with older mothers, young women are more likely to attend to the needs of their children than to their own health care. However, the needs of any child, especially an infected child, may become overwhelming, and young mothers may have problems with the consistent attention to detail required by complex antiviral regimens.

The constant demands of motherhood compete with the desire to participate in age-appropriate activities with peers. Young mothers appear to enjoy children during early infancy when babies are relatively compliant, offer novel experiences, and attract attention. As a child’s motor coordination develops, however, a mother’s frustration with setting and enforcing boundaries can make the inquisitiveness of a toddler seem “bad” or “mean” rather than typical and normal.

Providers Respond

Young mothers (and their children) benefit from services that help them build on individual strengths and encourage skills development, and experience proves the benefits of such comprehensive, future-affirming programs. Studies show that programs that offer an array of services—such as life-skills training, educational and vocational support, health care, case management, and counseling—produce long-term positive outcomes for teen mothers. Specific issues that require management include housing, income, transportation, food, child care, and medication.

The enormity of the management task combined with the characteristics of young mothers may put providers at risk of becoming frustrated and overwhelmed. Inexperienced youth require closer supervision and monitoring than older clients. Active case management requires frequent contacts, commonly outside of the office. The pace at which a young person gains the skills and maturity to child rear and self-care may seem slow. Additionally, many young mothers are physically and emotionally needy.

The result is that providers risk the impulse to become overly involved. The boundary between an invested, mentoring professional and a surrogate parent is not always clear. All too commonly, a provider’s emotional response to client behavior and decision making will cloud his or her professional judgement. For instance, many providers are shocked by some client behavior, particularly regarding pregnancy decisions, non-disclosure, unprotected intercourse, and non-adherence with medications. Emotional or punitive provider reactions interfere with effective behavior change and risk reduction. To guard against reflexive, judgmental responses, providers must arm themselves with self-awareness, patience, and persistence, seeking to help the adolescent find her own way at her own pace.

The key to working with adolescents who are parenting is balance. Balancing professional intervention with client initiative is particularly delicate with an infant or small child as the second “client.” The safety of the child outweighs the autonomy needs of the teen. Overall, providers must monitor and support their client’s efforts so adolescent mothers do not become overwhelmed, but teen mothers need to experience the consequences of their actions, both positive and negative, in order to learn how to exercise responsibility.


Authors

Sue Ellen Abdalian, MD is Associate Professor of Clinical Pediatrics and Head of the Section of Adolescent Medicine at Tulane University School of Medicine and Tulane Hospital for Children.

Karen Lingard Wright, MEd is the Adolescent Case Manager/Developmental Specialist at Family Advocacy, Care, and Education Services (FACES), a project of Children’s Hospital in New Orleans.

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Reducing Perinatal HIV Transmission


Zidovudine (ZDV; AZT) therapy, along with routine HIV counseling and voluntary prenatal testing, reduced perinatally acquired AIDS cases in the United States by 67 percent between 1992 and 1997, according to a nationwide study.

Researchers analyzed HIV surveillance data from 14 of 29 states that monitor HIV infection. Perinatal transmission is the cause of 90 percent of pediatric AIDS cases and nearly all new cases of HIV infection in children. AIDS diagnosis per year among children born to HIV-infected mothers peaked in 1992 with 907 infections. In 1994, the U.S. Public Health Service began recommending prenatal HIV testing and ZDV therapy for seropositive pregnant women to reduce perinatal HIV transmission.

By 1997, the number of cases of perinatal transmission dropped to 297. The decrease in perinatal transmission was partially due to more widespread prenatal HIV testing and ZDV use among HIV-infected mothers: 94 percent of infected mothers received prenatal HIV testing in 1997 compared to 70 percent in 1993, and 76 percent received prenatal ZDV treatment in 1997 compared to 28 percent in 1994. In addition, the percentage of HIV-infected children and their mothers who received any ZDV therapy increased from 7 percent in 1993 to 91 percent in 1997. Through June 1998, a total of 7,512 children were reported with perinatally acquired AIDS diagnoses.

Between 1992 and 1995, births to HIV-infected women decreased by 17 percent and perinatally acquired AIDS diagnosis decreased by 42 percent—a trend that continued into 1998. ZDV therapy reduces transmission rates from mother to child to an estimated 5 percent. In addition, PCP prophylaxis between 1992 and 1996 may have contributed to overall decreases in AIDS diagnoses among children; during that period Pneumocystis carinii pneumonia (PCP) declined by 67 percent.

Caring for Adolescents with HIV

Riddel J, Moon MW. Children with HIV becoming adolescents: Caring for long-term survivors. Pediatric Nursing. 1996; 22(3): 220-223,227,255. (University of California, San Francisco; and San Francisco Department of Public Health.)

Adolescents with chronic illnesses experience the same developmental transitions as other children, according to a review article that explores the dynamics of HIV-infected children growing into adolescence. For an HIV-infected adolescent, however, anticipating an early death may complicate developmental processes, and overprotective adults concerned about the child's illness may hinder normal adolescent feelings of self-reliance and independence.

Since the late 1980s, an increasing number of children with perinatally acquired HIV infection have survived into adolescence. Research suggests that slower disease progression can be the result of various factors, including earlier diagnosis, increased use of antiviral drugs, improved supportive care, absence of other infections, viral strain differences, and reduced psychosocial stress.

All adolescents, including HIV-infected teens, are likely to deal with issues of self-identity and sexuality. Understanding mental and physical sexual development may be complicated because some HIV-infected adolescents may feel they are “contaminated” or “poisoned.” Feelings of guilt or shame may also affect the sense of self and sexuality. In response to such feelings, providers may find it helpful to emphasize that HIV infection is not a reflection of an adolescent's entire self, but rather a medical condition making up one part of a person's whole being.

For providers working with adolescents, strict confidentiality is crucial to establish trust. It is necessary to explain to adolescent clients that suspicions of child abuse and certain communicable diseases—such as AIDS diagnoses—must be reported to state health departments. But, it may enhance an adolescent's willingness to discuss HIV infection if providers clarify that all other information cannot be shared with anyone, including parents, without client permission.
Pregnancy among Young Seropositive Women

In a multi-city study of 67 young HIV-infected women, 43 percent thought their friends would be happy and 56 percent thought their partners would be happy if the participant wanted a baby. On the other hand, 46 percent thought their friends would consider this “stupid,” but only 24 percent believed their partners would believe it to be “stupid.”

Participants—ages 13 to 24—were recruited from community-based service centers and adolescent medical programs in Los Angeles, San Francisco, Miami, and New York. Forty-four percent were African Americans, 27 percent were Latinas, 9 percent were White, 7 percent were biracial, and 13 percent were of other ethnicities. Eighty-seven percent of the women had been diagnosed with an STD sometime in their lives, and 69 percent had been pregnant before their HIV diagnosis. Thirty-eight percent of participants were unaware that medication could lower the risk of perinatal HIV infection and 17 percent were unaware that a baby could become infected through breast-feeding.

Although 25 percent of participants believed the rate of perinatal transmission to be much higher than it actually is, 42 percent of participants had become pregnant after learning about their HIV infection, with 71 percent carrying to term, resulting in 25 percent of babies becoming infected. Participants who had become pregnant after learning about their HIV infection were just as likely as those who did not become pregnant to answer HIV knowledge questions incorrectly, even though they should have received information on mother-to-child HIV transmission as part of prenatal care. Since HIV diagnosis, 53 percent reported using condoms during sex “every time,” 15 percent “most of the time,” 23 percent “occasionally or rarely,” and 9 percent “never.”

Growing Up with HIV
Grubman S, Gross E, Lerner-Weiss N, et al. Older children and adolescents living with perinatally acquired human immunodeficiency virus infection. Pediatrics, 1995; 95(5): 657-663. (New Jersey Medical School; National Pediatric and Family HIV Resource Center; and Children’s Hospital of New Jersey, Newark.)

In a small study predating widespread combination therapy use, nearly 25 percent of children and adolescents infected with HIV around the time of birth were asymptomatic and 75 percent experienced serious HIV-related symptoms. Increasing symptoms may be explained by the fact that children with HIV are living longer: between 1989 and 1995, the average age of survival for children with perinatally acquired HIV increased from six years to nine years.

The study included 20 boys and 22 girls between the ages of nine and 16 who were perinatally infected with HIV and who were receiving care at the Children’s Hospital AIDS Program (CHAP) in Newark, New Jersey. Psychosocial status evaluation showed that 76 percent of the children became orphans when their mothers died of AIDS-related illness.

Like other chronic illnesses, HIV infection can contribute to school absences for medical visits, lead to recurrent hospitalizations, make children dependent on medications, and cause children to look or feel “different.” School absences caused by acute illness, hospitalization, and doctors’ visits contributed to poor performance for 34 percent of the children. In addition, HIV-related stigma may limit disclosure of a child’s HIV status, and this lack of disclosure may compromise a child’s health by limiting the number of people who are able to administer medications and assess overall health.

Next Month

Even as improved HIV treatment saves many lives, one of the greatest challenges remains: living with loss and grief. In fact, because many have seen their losses multiply over the epidemic’s two decades, a large number have inadequately resolved an ever-accumulating mass of grief. In the February issue of FOCUS, Peter Goldblum, PhD, MPH, former Director of the Stanford AIDS Caregiving and Bereavement Study and the author of a new UCSF AIDS Health Project Monograph on the topic, proposes a new model for working with clients who are dealing with loss.

Goldblum reviews the psychodynamic and cognitive theories that define bereavement and synthesizes an Integrative Model of AIDS Bereavement that takes into account the particular way in which each person’s grief manifests.
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