HIV can be transmitted perinatally, that is from a woman to a fetus during pregnancy or from a mother to a child during delivery or immediately following birth. Perinatal transmission is also referred to as vertical transmission.

RESEARCH UPDATE

It is estimated that as many as 80,000 women of reproductive age in the United States might be infected with HIV. Epidemiologists believe that each year from mid-1988 to mid-1990, there were 6,000 births to HIV-infected women in the United States.

Probability of Transmission

While early studies of perinatal HIV transmission showed that as many as 60% of children born to a mother with HIV were themselves infected, more recent research has found this high rate to be inaccurate. Studies in 1991 and 1992 have commonly found transmission rates of about 25%. One study reported a transmission rate as low as 14%. Clinicians generally indicate that children born to women with HIV have a 25% chance of being infected.

Several factors may affect transmission rates. Research has suggested that transmission rates may be higher for women with relatively low T-helper cell counts, those in whom p24 antigen is present, and those who are at more advanced stages of illness.

It is not possible to determine if a woman with HIV will bear an infected child. A woman's history of giving birth to children with or without infection is not an indicator of whether future children will be infected. A small study showed that children born to women who seroconverted during pregnancy were at no greater risk of HIV infection than children born to women who were seropositive at the time they became pregnant.

Methods of Transmission

Much remains unknown about the specific ways in which HIV is transmitted from a woman to a fetus or child, but most researchers assume that transmission occurs through more than one route. Researchers have speculated that transmission can occur throughout pregnancy at the time of conception or at some point during the embryonic or fetal stage.

Probability of Transmission

While early studies of perinatal HIV transmission showed that as many as 60% of children born to a mother with HIV were themselves infected, more recent research has found this high rate to be inaccurate. Studies in 1991 and 1992 have commonly found transmission rates of about 25%. One study reported a transmission rate as low as 14%. Clinicians generally indicate that children born to women with HIV have a 25% chance of being infected.

Several factors may affect transmission rates. Research has suggested that transmission rates may be higher for women with relatively low T-helper cell counts, those in whom p24 antigen is present, and those who are at more advanced stages of illness.

It is not possible to determine if a woman with HIV will bear an infected child. A woman's history of giving birth to children with or without infection is not an indicator of whether future children will be infected. A small study showed that children born to women who seroconverted during pregnancy were at no greater risk of HIV infection than children born to women who were seropositive at the time they became pregnant.

Methods of Transmission

Much remains unknown about the specific ways in which HIV is transmitted from a woman to a fetus or child, but most researchers assume that transmission occurs through more than one route. Researchers have speculated that transmission can occur throughout pregnancy at the time of conception or at some point during the embryonic or fetal stage.
**HIV in California Childbearing Women**

**Rates per 10,000 Women Who Gave Birth**

<table>
<thead>
<tr>
<th>Region</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Women</td>
<td>7.4</td>
</tr>
<tr>
<td>Los Angeles</td>
<td>9.6</td>
</tr>
<tr>
<td>San Francisco Bay Area</td>
<td>12.9</td>
</tr>
<tr>
<td>Other California Areas</td>
<td>4.4</td>
</tr>
</tbody>
</table>

**Infection Rates by Age**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 25</td>
<td>8.5</td>
</tr>
<tr>
<td>25-34</td>
<td>3.7</td>
</tr>
<tr>
<td>35+</td>
<td>9.0</td>
</tr>
</tbody>
</table>

*Based on HIV antibody tests of 135,808 newborns in the third quarter 1988.

**Progression of Disease**

Preliminary studies have shown that pregnancy did not affect disease progression in women with HIV. Studies comparing pregnant, HIV-infected women to uninfected pregnant women have found little or no difference in the rate of clinical and immune system deterioration.

However, HIV symptoms and opportunistic infections can be more serious when they occur during pregnancy compared to outside of pregnancy. Fatigue, anorexia, weight loss and shortness of breath are symptoms of both HIV infection and pregnancy. When these symptoms occur as a result of pregnancy, the added presence of HIV can make them more serious. Also, because they are common symptoms of pregnancy, clinicians may not see them as signs for HIV, and therefore may fail to take steps to prevent further HIV disease progression.

Studies have found no significant differences in delivery terms or pregnancy complications between asymptomatic HIV-infected women and uninfected women. In a study comparing infants born to HIV seronegative mothers with those born to seropositive mothers — without regard to the mother’s health status — there were no significant differences in birth weight or size. However, one small study found that HIV-infected women were more likely than uninfected women to have premature labor and to give birth to low birth-weight infants. More research is being conducted.

**Detecting HIV in Infants**

Traditional antibody testing methods are not reliable in detecting HIV infection in newborns. During the first 12-15 months after birth, a baby may continue to have its mother’s antibodies, regardless of whether the child is infected with HIV. After this period, a baby loses its mother’s antibodies and, if infected, develops its own.

However, a recently developed test may offer promise at determining infant infection as early as six months after birth. This test measures proteins called IgA antibodies, which, unlike antibodies measured by standard HIV antibody tests, do not travel across the placenta to the fetus. This simple and relatively inexpensive test, which costs about $50, may reveal the child’s, rather than the mother’s, response to HIV. In addition, the experimental and costly polymerase chain reaction (PCR) laboratory test can detect the presence of HIV in infants at least six months old.

**Treatments and Pregnancy**

In initial studies, pregnant women have responded as well as other HIV-infected people to treatment with AZT. While one report suggested that recommended doses of AZT are not harmful to women or fetuses, the long-term...
effects of the drug in pregnancy are not known, and an early study of AZT at high concentrations in animals found fetal damage. Some researchers have speculated that AZT can prevent HIV transmission from mother to fetus, but this has not been proven.

Most other drugs, including antiretrovirals such as ddI, ddC and therapies for opportunistic infections, have not been well-studied among pregnant women, and caution is urged in using them.

Testing and Reproductive Decision-Making

Most groups, including the federal Centers for Disease Control (CDC), recommend voluntary HIV counseling and testing for all women of childbearing age who are at risk for HIV infection.

The American Medical Association (AMA) issued policy recommendations stating that HIV testing for women of childbearing age is often advised. However, the AMA has stated that, "A policy of mandatory screening for pregnant women is not justified based on traditional public health criteria or other grounds." The AMA's recommendations also reject counseling and screening policies that are directive and that interfere with women's reproductive freedom.

Studies have found that a woman's HIV status is not the most important factor to influence decisions to continue or terminate a pregnancy. Decisions are based on many factors, including family and social relations, cultural and religious beliefs, economic circumstances and childbearing history. Factors that influence one woman to continue pregnancy may influence another to terminate. For instance, one woman may view the possibility of having a child as a danger to her physical health, while another may see the presence of a child as beneficial to her psychological health.

One study of injection drug-using women found that mother-child separation was the most consistent predictor of a woman's decision to continue or terminate pregnancy. Women who did not live with their children, after children had been removed by social service workers, were more likely to continue pregnancy than women who lived with their children.

In addition, women who terminated pregnancy were more likely to have known about their infection for a longer time than women who chose to continue pregnancy.

Some women with HIV may believe that because of their infection they cannot become pregnant. Injection drug users (IDU), in particular, may believe this because drug use and related medical problems may result in irregular menstrual periods. However, there is no reason to believe that women with HIV are less likely than uninfected women to become pregnant.

A Related Issue: Health of Infants with HIV

Through March 1992, children under the age of 13 represented nearly 2%, or 3,692, of the 218,301 AIDS cases reported in the United States. In California, children under age 13 represented .07%, or 279, of 41,042 AIDS cases. Most of the children's cases nationally and in California were attributable to perinatal transmission.

On average, HIV disease progresses more rapidly in infants than in adults. About 20% of infants with HIV develop a serious HIV-related illness within the first 18 months of life, and many die during this period. However, infants may live for many years without symptoms. Newborns infected through perinatal transmission have a shorter life expectancy than those infants infected through blood transfusions.

Bacterial infections are common among infants with HIV, while infections like toxoplasmosis and cryptococcal meningitis appear less frequently than they do among adults. Kaposi's sarcoma (KS) rarely affects children, but children often develop lymphocytic pneumonia, which rarely occurs in adults.

Children also develop pneumocystis carinii Pneumonia (PCP) and other severe infections at a higher T-helper cell levels than adults. In one study, children, all less than 40 months old, survived a median of only two months after a diagnosis of PCP.

The Food and Drug Administration (FDA) has approved AZT therapy for children and infants at least three months old who show symptoms of disease or abnormal laboratory test results. Researchers report AZT works as well for children as for adults. Similar side effects are also reported.

Preventive treatments generally begin at much earlier stages of disease progression in children than in adults. For example, children may receive PCP prophylaxis at less than a year old regardless of their T-helper cell count. Fewer drug studies are being conducted in children compared to adults, though an increasing number of trials are available for children.
References


6. Ryder RW, Manzila T, Baende E. Evidence from Zaire that breast-feeding by HIV-infected mothers is not a major route for perinatal HIV-1 transmission but does decrease morbidity. AIDS. 1991; 5: 709-714.


Infant Health at Birth

<table>
<thead>
<tr>
<th>Babies Born to Seropositive Women (n=63)</th>
<th>Babies Born to Seronegative Women (n=57)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight (in grams)</td>
<td>2,811*</td>
</tr>
<tr>
<td>Length (in centimeters)</td>
<td>47.94</td>
</tr>
<tr>
<td>Head (in centimeters)</td>
<td>33.23</td>
</tr>
</tbody>
</table>

*Numbers given are averages. Differences are not statistically significant.

IMPLICATIONS FOR COUNSELING

Reproductive issues are complex and highly specialized. They are best discussed in depth with physicians and family planning and other counseling specialists who have experience and training to deal with these issues. While HIV test counselors cannot take on the role of family planning providers, reproductive issues are a relevant and essential topic for many test counseling sessions. HIV test counselors can provide basic information, offer referrals for follow-up counseling and care, encourage clients to learn more and help them understand the importance of making decisions affecting reproductive issues. Counselors must refrain from making value judgments or responding in any way that might inhibit clients' choices.

The contact between counselors and female clients with reproductive concerns can be especially valuable because, regardless of antibody status, many women of childbearing age do not have regular contact with medical or public health workers. Most women who give birth to antibody-positive children discover their own antibody status after delivery, and generally only after an infected child becomes sick.

The Basics

Many clients know little about the relationship between HIV and pregnancy. Even an HIV-infected woman who has had several children may be unaware that she can...
transmit HIV to an unborn child, or that she can give birth to an uninfected infant.

During pre-test counseling, make clients aware of the following information related to HIV and reproduction. Reiterate this information in post-test counseling.

- HIV can be transmitted from a mother to a child. Currently, it is believed that a child born to an infected mother has about a 25% chance of being infected. Aside from the risk of transmission, HIV does not appear to affect the course of pregnancy or the outcome of delivery, though this issue is still being studied.

- Pregnancy does not generally have an adverse effect on the health of a woman with HIV, though this too is still being studied.

- HIV disease usually progresses more rapidly in infants infected perinatally than in adults.

- HIV does not appear to affect a woman’s ability to become pregnant.

- A woman has the right to decide whether she wishes to continue or terminate pregnancy. Termination becomes increasingly complicated after the 12th week of pregnancy, and some clinics refuse to provide services to women with HIV. Physicians and family planning specialists can help clients understand their options.

- There are signs and symptoms of HIV disease, and while it is always important for people with HIV to monitor these, it is especially important to do so during pregnancy.

Allow clients to ask questions about these topics. Acknowledge that many issues related to reproduction and HIV, including specific methods for perinatal transmission, are unresolved.

Detail the benefits of knowing HIV antibody status for the health of the mother and her unborn child, including the ability to implement early intervention and the value of being emotionally prepared. Resist viewing the test as more imperative for clients who are pregnant or considering pregnancy than for other clients; it is important that counselors remain objective and support whatever testing decisions these clients make.

Remember that sexual transmission of HIV remains an issue for a woman even if she is having a child. Reinforce safer sex messages, and discuss the relevance of safer sex to HIV and reproduction.

**Decision Making**

In post-test counseling, encourage clients to explore the role of reproductive issues in their lives and outline reproductive options in a judgment-free environment. Discuss specific options only if clients wish to discuss them.

In post-test counseling, as well as in pre-test counseling, encourage clients to avoid making decisions about continuing or terminating pregnancy during the counseling session. At this time, clients may be overwhelmed by information about reproduction and HIV and by the disclosure of a positive test result. Most often they will benefit from being able to make a decision over time, and after further counseling from a physician or specialist. If a client appears to have made a decision before the counseling session, respect this.

The counselor’s role at this time is to establish an atmosphere in which clients will feel comfortable discussing how they feel about their positive test results and about reproductive issues. This may be the first time the client is able to focus on herself and her needs. It is important to help the client separate her needs from the potential needs of a child.

In general, a primary role of HIV test counselors is to direct clients to prevent HIV transmission. Because of this, a counselor may feel a responsibility to offer directive counseling to a seropositive pregnant woman who is at risk for transmitting HIV to a child, without realizing the other issues that are relevant.

In helping clients explore reproductive options, consider the following factors:

- **Belief systems.** Personal beliefs, especially religious, moral and ethical attitudes about reproductive issues, influence a person’s values and perceptions of acceptable risks.

- **Relationships.** The dynamics of relationships with friends and lovers or spouses affect many areas of decision making, including the extent to which people make decisions independent of others and others’ expectations. A supportive partner may make it easier for a mother with HIV to cope with raising an infected child.

- **Societal role.** The extent to which a person feels her role in society is to reproduce or raise children can affect feelings of responsibility, personal pride or status in the community. While often viewed as beneficial, this can be a drawback if a woman feels pressure to conform to a societal role she does not embrace.

- **Feelings of self worth.** Childbearing, and the process of carrying an embryo to the point of having a baby, may provide affirmation that the client is healthy or that she is fully a woman.

- **Reproductive history.** The number of children and the number of terminations a woman has had can influence her desire to have children. Some women with HIV may choose to terminate a first pregnancy, but decide to have a child during a subsequent pregnancy. Or, a woman who has a child with HIV may believe the chances are good that another child will not be infected.
• Personal perceptions of risk. Perceived risk often depends on the types of risk, illness or loss a person has experienced. For instance, while some clients may consider a 25% chance of perinatal transmission to be high, for others this risk may not be as significant.

• The health effects of having and raising a child. Childbirth and raising a child can have both negative and positive effects on a woman’s health and on her ability or willingness to take care of her health.

• Health of a child. Considerations related to the health of an HIV-infected child include the ongoing needs of a child with HIV and an infected parent’s ability to meet his or her child’s special needs.

Explore various factors that may influence a woman’s decision-making by asking about her feelings toward having a child and knowing that the child might be infected. Then ask about her feelings about potentially caring for an infected child.

Other Factors
Because women often take responsibility for caring for others and may put such responsibilities ahead of taking care of themselves, it is important that women with HIV, especially pregnant women, recognize this potential imbalance. Encourage these clients to make a commitment to seek medical care, eat well, rest properly, exercise regularly and take the time to plan for their future.

Parents with HIV disease, men and women, must consider the lives of their children before they are born. Begin this process by posing questions, such as who will care for children if parents become ill? And, who will be able to care for the child and take on financial responsibility if the child becomes ill? Encourage clients to discuss these questions with friends, family members, medical providers and social workers.

Women should consider the effects of treatments on themselves and their children. The antiviral drug AZT is probably safe for pregnant women while posing little threat to the developing fetus, but the long-term effects of AZT are not known, and other treatments may be harmful. Asymptomatic women may be unsure whether to begin treatments either before or after having a child. Researchers believe that many treatments have similar effectiveness and safety in children as in adults, but most treatments have been studied for a relatively short time.

Encourage clients to talk to physicians and pediatricians who are knowledgeable about HIV and pregnancy, and can discuss the effects of treatments on pregnant women. Finally, teach pregnant women how to detect signs and symptoms of HIV infection, and advise them to promptly report symptoms.

Reproductive Concerns of Antibody Negative Women
As with all clients, encourage retesting for seronegative women who have engaged in unsafe behaviors over the prior six months—the “window period” for developing HIV antibodies — or those clients who believe themselves to be at risk for infection. For pregnant women, however, clinicians urge that this retest be performed no later than the 26th week of pregnancy. Termination is not performed beyond this point.

Many women seek HIV antibody testing because they are considering pregnancy. For those who test negative, be prepared to talk about their risk of future infection. It is important that they and their partners retest antibody negative outside the infection window period.

Remind clients wishing to become pregnant through vaginal intercourse that their health and the health of their unborn child is dependent on the degree to which they trust their partners’ declarations that they have tested negative and have not engaged in unsafe sex with others in the past six months.

Referrals
Because of the complex technical and personal nature of reproductive issues, it is important that counselors provide relevant referrals of people who are familiar with HIV in pregnancy. Give clients referrals to counselors at
Case Study

Margaret is a 22-year-old who is two months pregnant and has just been told in the post-test counseling session that her HIV antibody test result is positive. She wants to continue her pregnancy and have a baby, but says she is scared. She is afraid of the possible reactions of her friends and family. Her boyfriend is unaware of Margaret's pregnancy, but has said before that he does not wish to be a father. Margaret is also scared that without support from others, no one will care for her child if she becomes ill. Another concern is that she and her family have little money to care for an infected child.

Counseling Intervention

Margaret may be trying to answer too many questions. Help her understand that her questions and concerns are significant, and can be overwhelming, but they do not all need to be answered immediately.

Help slow Margaret's pace by taking her back to basic topics. Concentrate on what her feelings are for herself at the moment, and what her antibody status means to her. Make sure she understands the reliability and meaning of her result.

Continue by discussing the basics of reproductive issues presented in the Implications for Counseling section, including the potential risk to the fetus. Assess Margaret's stage of pregnancy. Taking sufficient time with basic topics may help Margaret feel greater control. At this point, however, Margaret may be emotionally "shut down" as a result of the many issues she is attempting to deal with, including an antibody positive test result.

Consider other issues with Margaret. Ask her what it means for her to have a baby, and what it would mean if her baby has HIV. Such questions are designed to help Margaret understand the issues that may affect her as she begins to make decisions. Looking at these questions in the safety of the counseling session may give Margaret more confidence in her decision-making ability.

Help Margaret understand that her concerns are significant, and that her feelings are valid. Let her know that it is all right to feel disappointment and fear. And reemphasize that she is entitled to make her own decisions regarding pregnancy.

Emphasize that it is important for Margaret to be able to talk about her feelings, thoughts and concerns with someone who will support her without attempting to direct her decisions or make decisions for her. Begin to consider others who Margaret trusts, and who she believes will listen to her. Among possible candidates are a friend, family member, medical provider, nurse practitioner, counselor or social worker. If Margaret does not have a person already in her life to talk to, provide her with at least two referrals who can listen and help. As the test counseling session continues, she may think of someone she can talk to.

Ask Margaret where she plans to go after the test counseling session. Help her see the potential value of disclosing her status to another person, either someone in her life already or a social service or family planning provider.

State to Margaret the importance of protecting her health, and the importance of caring for herself. Make sure she understands behaviors that transmit HIV, and stress that she can transmit HIV to others.

family planning clinics, obstetricians/gynecologists and nurse practitioners so they can receive information to make decisions and receive ongoing care. Also, offer referrals to social workers, private therapists and support groups. Counselors can learn about the nature of counseling provided by specialists by calling service providers and asking them to describe their counseling approach with pregnant women who have concerns related to HIV.

Health care for pregnant women with HIV is available through specialized primary care clinics and high-risk prenatal clinics in some areas of the state. To learn more about these providers, call a regional AIDS hotline. In Southern California, call (800) 922-2437. In Northern California, call (800) 367-2437.

It can be valuable for antibody positive women who are pregnant to discuss their concerns with someone they trust to be supportive and non-directive. Help clients identify other people in their lives — friends or family members or social service or health care providers — who can provide this support. Discuss how the client might tell that person and how the client can prepare for various reactions. If the client has no one in her life she feels will be supportive, offer an additional referral to a health care or social service provider who can serve this role.
**TEST YOURSELF**

1. In the United States, how many women of reproductive age are believed to be infected with HIV? a) 5,000, b) 1,000, c) 60,000, d) 4 million.

2. True or False: Clinicians generally state that children born to HIV-infected women have a 25% chance of being infected themselves.

3. True or False: Studies have found that younger women are more likely than older women to transmit HIV to a child.

4. True or False: Researchers speculate that perinatal HIV transmission occurs at what period? a) conception, b) during delivery, c) after conception but before delivery, d) all of the above are possible.

5. True or False: An infant can test antibody positive without actually being infected with HIV.

6. Recent research finds that pregnancy has what effect on women with HIV? a) it greatly speeds progression, b) it is believed to have little effect on progression, c) it stops progression.

7. True or False: Women should not take the drug AZT because this drug has conclusively been found to cause human fetal damage.

8. True or False: One small study found that women with HIV who terminated pregnancy generally had known about their infection for a longer period than women who continued pregnancy.

**DISCUSSION QUESTIONS**

- Counselors may hold strong personal views on continuing or terminating pregnancy in the face of HIV infection. How can counselors ensure that these views are not expressed to the client?

- The Case Study presented a woman who wished to continue her pregnancy. How would the counseling intervention be different for a client who wished to terminate pregnancy?

- Some women may enter pretest counseling, but may not wish to be tested. To what extent should testing be encouraged? What counseling can be offered to these clients?

- Because risk reduction is a primary role for counselors, it may be difficult not to provide definite instruction to a client in making a decision around continuing or terminating pregnancy. How can counselors be successful at this?

- Women who are not infected with HIV may wish to become pregnant, but fear being infected when they are attempting to conceive a pregnancy. What can be said to such a client?

- Clients are likely to come in contact with people who have definite views related to HIV and pregnancy. How can counselors prepare clients to deal with these individuals and make decisions on their own?

Answers to Test Yourself:

1. C. As many as 80,000 women of reproductive age in the United States might be infected.

2. True. Studies have found the rate of infection from mother to child is generally about 20% to 25%.

3. False. Studies have not found a link between perinatal transmission and age.

4. D. It is not conclusively known when HIV is transmitted. Researchers speculate it may occur at the time of conception, time of delivery, or some period in between.

5. True. Because an uninfected baby can carry its mother's antibodies for up to the first 15 months after birth without being infected, the child can test antibody positive in the absence of infection.

6. B. It is believed that pregnancy has little effect on HIV disease progression in pregnant women.

7. False. AZT has not been shown to cause fetal damage.

8. True.

**HIV Counselor PERSPECTIVES**

PERSPECTIVES is an educational publication of the California Department of Health Services, Office of AIDS, and is written and produced by the AIDS Health Project of the University of California San Francisco. Reprint permission is granted, provided acknowledgment is given to the Department of Health Services.

Information in PERSPECTIVES is based in large part on input from antibody test counselors and other health professionals. Among those who had a significant influence on this issue are: Graciela Morales, Bonnie Coates, Michelle Berlin, Bonnie Dattel, Barbara Garcia and Amanda Newstetter.

This issue of PERSPECTIVES published in June 1992.

PERSPECTIVES is printed on recycled paper.

**Volume 2, Number 3**

Director, AIDS Health Project: James W. Dilley, MD.

Writer and Editor, PERSPECTIVES: John Tighe.

Clinical Consultants: JD Benson, MFCC; Marcia Quackenbush, MFCC; Jaklyn Brookman, MFCC.

Publications Manager: Robert Marks.

Technical Production: Leslie Samuels; Joseph Wilson.

Administrative Support: Roger Scroggs.

Department of Health Services, Office of AIDS, P.O. Box 942732, Sacramento, CA 94234, (916) 445-0553; AIDS Health Project, Box 0884, San Francisco, CA 94143, (415) 476-6430.