Assisting Healthy HIV-Positive Parenthood
Cynthia Feakins, MSN, NP

For many people, HIV has truly become a chronic, manageable illness. At the same time, medical advances have allowed tremendous reductions in mother-to-child HIV transmission. Since so many HIV-positive men and women in the United States are of “childbearing age,” having children without transmitting HIV is a key concern for HIV-positive men and women and their partners. This article explores the medical interventions that can help people with HIV (particularly mixed-HIV-status couples) become parents with the least risk of transmission to their partners and children.

Maternal-Child Transmission
Children who acquire HIV from their mothers become infected through “vertical transmission,” that is, contact with the mother’s blood during pregnancy or delivery, or later, through contact with her breast milk. Since HIV is not transmitted genetically, fathers do not transmit HIV directly to children during reproduction. Rather, an HIV-positive father might transmit HIV to his female partner and then she might transmit HIV to the couple’s child. Thus, in the case of a mixed-status couple with an HIV-positive father, the prevention focus is on keeping the mother (and thus also the child) HIV-negative.

The reduction in maternal-child HIV transmission is one of the greatest success stories of the HIV antiviral era. In the United States, before the use of HIV antiviral therapy, HIV-positive women had a 25 percent chance of transmitting the virus to their infants during pregnancy and birth, with an additional 16 percent chance of transmitting HIV through breastfeeding. In the early 1990s, the Pediatric AIDS Clinical Trials group found that zidovudine (AZT; ZDV) given to the mother during late pregnancy and delivery and to the non-breastfed-infant for six weeks reduced HIV transmission risk to 8 percent. More recently, studies of children born to HIV-positive mothers have documented transmission rates below 1 percent. In these studies, infants received ZDV, were not breastfed, and were born to women with viral loads below 1,000 who also took combination antiviral therapy.

By Choice or By Chance
People come to HIV-positive parenthood in a variety of ways. Some people know their status before conceiving, understand how low transmission risks are with treatment, and consciously choose to parent. Others receive an HIV diagnosis during pregnancy and must decide whether to continue the pregnancy. Many HIV-positive people experience fears of transmitting HIV to their children, fears about the effect of pregnancy on the mother’s health, and concerns about disclosure of their HIV status.

HIV-positive people also experience unplanned pregnancies—and they are in good company. One recent estimate found that roughly half of all pregnancies in the United States are unplanned. Some HIV-positive people and their partners do not use contraceptives, or their contraceptives fail. Some express beliefs such as, “If I get pregnant, it means it was meant to be.” These women often see pregnancy as a gift, but not necessarily a choice.

Often ambivalence and fear are central to “nondecisions” about parenthood. In part this is because of the stigma that HIV-positive people still face when they openly desire children. Despite the fact that medical advances make it unlikely that an HIV-positive mother receiving treatment will give birth to an HIV-positive
Editorial: Child Support
Michelle Cataldo, LCSW, Clinical Editor

Few decisions are as life-altering as the choice to have a child. I turned 40 recently (without children) and am surrounded by friends who are parents or are actively trying—to become parents. I’ve spent much of the last several months reflecting on what parenthood means to me: a connection to the future, the most serious commitment I can imagine, and intense intimacy right from the beginning. From the outside, it seems both exhilarating and daunting.

In this issue of FOCUS, Cynthia Feakins and Bill Blum tackle the topic of choosing parenthood with an added hurdle: HIV disease. Although there has never been a better time to be an HIV-positive parent—at least in terms of preventing HIV transmission to children—obstacles to having children remain. Stigma, misinformation, and provider discomfort in discussing options all discourage some people from considering parenthood or from being open about their desire. In addition, many people fear not only potential HIV transmission to their children, but also the long-term effects of preventive medications.

Feakins, a nurse practitioner at the Bay Area Perinatal AIDS Center in San Francisco, discusses some of these challenges and the ways that medical providers and HIV-positive or mixed-serostatus couples can work together to achieve a healthy pregnancy and birth. Blum, a clinician and HIV services administrator, shares his personal journey to fatherhood as a gay man with HIV.

Both Feakins and Blum identify the barriers that HIV-positive people, especially men, face in obtaining reproductive services to assist conception. It is exciting to note that, as of this January, California law finally allows “sperm washing” and artificial insemination on behalf of HIV-positive men.

Of course, this assistance often comes at a price, and many HIV-positive people already face financial hardship. Further, although a healthy conception and birth are a few of the first challenges of HIV-positive parenthood, they are far from the last. Providers may not be able to help with all of these concerns, but we can create a safe place for people to talk about their parenting dreams, and offer them information and options to make them real.

References

Child Support

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may cost hundreds of dollars per attempt, or donor eggs and surrogacy, an even more costly proposition.

For those in mixed-status couples who desire both parents to be biologically related to the child, there are several possible scenarios. Women who are HIV-positive have a low-technology option: home insemination. This “turkey baster” method involves using a syringe without a needle to place the ejaculate into the vagina, eliminating the risk of transmitting HIV to their male partners. Many women pinpoint the best time to inseminate by using ovulation predictor kits, which are easily available over the counter and which detect hormones in the urine. Women who have difficulty conceiving using this method can attempt more advanced reproductive therapies, such as intrauterine insemination or in vitro fertilization, discussed below. The key to the delivery of an HIV-negative child is reduction of viral load throughout—and especially late in—pregnancy and during delivery.

When the potential father is HIV-positive, transmission prevention is more complex and often more expensive. The safest and most costly options involve “sperm washing.” While HIV is found in seminal fluid and some other cells in ejaculate, it is not found in sperm itself, so the “washing” process separates sperm from the seminal fluid.4,6 Then the sperm sample is tested for HIV, and if HIV-negative, it can be used for conception in several ways: vaginal insemination (similar to the “turkey baster” method above); intrauterine insemination (IUI) (sperm is deposited by a medical provider directly into the uterus); in vitro fertilization (IVF) (a medical provider uses the sperm to fertilize eggs outside the woman’s body and then transfers the eggs to the woman’s uterus); or intracytoplasmic sperm injection (ICSI) (a sperm is injected directly into an egg).4,6 The costs associated can range from many hundreds (sperm washing, vaginal insemination, or IUI) to many thousands of dollars (sperm washing, IVF, or ICSI).4

A less costly, but also less safe, means of reducing the risk of male-to-female transmission involves tracking ovulation and timing unprotected intercourse to the woman’s most fertile period. Ideally, the male partner has sought to reduce his viral load with HIV antiviral treatment. Although reducing the blood viral load to undetectable levels reduces the amount of HIV in the semen, HIV may still be present in semen even when it is undetectable in the blood.5 Semen analysis—the assessment of the sperm’s motility, quantity, and shape—can also help determine whether pregnancy is likely to be successful and therefore worth the risk of unprotected intercourse.

One recent study of 22 serodiscordant Swiss couples used preexposure and postexposure prophylaxis to achieve a high (70 percent) pregnancy rate without any HIV transmission. In this study, HIV-positive male partners in these couples took HIV antiviral drugs for a period of time. The semen sample was then tested for HIV, and if it was HIV-free, couples used ovulation predictor kits to time intercourse. Finally, female partners took one dose of Tenofovir before sexual exposure and another dose 24 hours after exposure. While these results are encouraging, such semen testing is not widely available.5

**Barriers to Conception Assistance**

Early in the epidemic, gynecologic and reproductive associations discouraged HIV-positive people from having children because of concerns about disease transmission. Early in this decade, these official position statements were revised to remove these recommendations.6 By 2007, only California and Delaware forbade the use of assisted reproductive technologies to help the partners of HIV-positive men achieve pregnancy.

New legislation, which took effect in January 2008, allows serodiscordant couples in California to use assisted reproductive technologies (such as sperm washing, IVF, and ICSI) as long as both the HIV-positive sperm donor and the female recipient of the sperm understand and consent to the health risks, and as long as the sperm is processed to reduce infectiousness.7
Supporting Transmission-Free Pregnancy

When an HIV-negative woman achieves pregnancy with an HIV-positive partner, she should be tested for HIV as early as possible and at intervals throughout the pregnancy. If found newly HIV-positive, she should begin HIV antiviral treatment as soon as possible. This is critical because early HIV infection is associated with extremely high viral loads, and high maternal HIV viral load is the strongest predictor of maternal-child HIV transmission. Providers may also advise pregnant HIV-negative women with HIV-positive partners about the option of postexposure prophylaxis. If, for example, a condom breaks during sex, treating the woman with HIV antiviral medications can lessen the chances of her seroconversion.

In general, pregnancy does not worsen HIV disease. Nausea and vomiting may make it difficult to adhere to HIV antiviral medications during the first trimester. Women who would not otherwise take HIV antiviral medication during this period may delay taking it until pregnancy-related symptoms resolve.

It is essential that HIV viral load be suppressed during the latter part of pregnancy and during delivery. Among women who do not breastfeed, two-thirds of the cases of mother-to-child transmission occur during the birth process, presumably because of exposure to maternal blood and body fluids. The remaining one-third occurs during pregnancy, generally late in pregnancy, through mechanisms that are not fully understood. Even if a mother takes precautions only by taking medication during delivery and by giving medication to her infant, the transmission rate for that infant can drop from 25 percent to 10 percent.

Most HIV-positive women can deliver their babies vaginally. Cesarean section is beneficial only for women who are co-infected with hepatitis C or who have HIV viral load counts over 1,000. In addition to HIV antiviral therapy during pregnancy, the HIV-positive mother receives intravenous zidovudine, ideally for three to four hours before delivery. The newborn then receives zidovudine syrup for six weeks after birth.

The Loss of Breastfeeding

Rather than breastfeeding their infants, mothers in developed countries are strongly advised to use formula or banked human milk for infant feeding. Many HIV-positive women feel the loss of breastfeeding deeply. They worry that they are not sharing the health benefits of nursing with their infants and that they are missing out on the emotional bonding—as well as the economy and convenience—that nursing offers.

Mothers who have not disclosed their HIV status may face well-meaning friends, relatives, and even service providers who offer to help them to establish breastfeeding. This often occurs during the first few weeks after delivery when milk may be leaking from the breasts and the infant is showing signs of wanting to feed. While women are encouraged to say that they are formula feeding for "medical reasons," rather than disclosing their HIV, many women find the loss of breastfeeding to be very painful, especially in cultures in which breastfeeding is the norm.

Testing the Newborn

Because maternal HIV antibodies are present in the infant for up to 18 months after birth, antibody testing will not accurately detect HIV infection in newborns. Instead, it is necessary to test for the presence of the virus itself. Viral DNA testing done at birth reflects whether transmission occurred before birth, while later tests done at two weeks, four weeks, and four months, reflect whether transmission occurred during birth. If all tests up to and including the four-month test are HIV-negative, the infant is presumed to not be infected with HIV. This assumes that the mother is not breastfeeding, in which case ongoing testing is necessary.

The U.S. Public Health Service Task Force guidelines recommend that, during the time between the end of zidovudine prophylaxis at six weeks and the four-month test, parents give prophylactic medication to prevent Pneumocystis carinii pneumonia (PCP). When the child is 18 months of age, an HIV-negative antibody test result can demonstrate "seroreversion," the disappearance of maternal HIV antibodies.

Conclusion

Certainly, people with HIV face special challenges when contemplating conceiving and having a child. Thanks to medical and legal advances, providers are better able than ever before to support mixed-status couples to conceive and to enable HIV-positive women to experience a healthy pregnancy and delivery. Today, the wonderful reality of having a healthy child is possible for the vast majority of men and women living with HIV.
I became a father at the age of 40, after having been HIV-positive for more than 10 years. My family includes my son, his bisexual mother, and my male partner of seven years, as well as our families and friends. Our son just celebrated his second birthday—full of laughter and in love with trucks, balls, and animals. While my desire to parent was always strong, my HIV diagnosis initially threatened this goal. I am writing now about my journey to parenthood in the hope that my family’s story will help others to realize their own parenting dreams and to give voice to a community of families that is often hidden.

Coming Out

In the early 1980s, as a 17-year-old college freshman, I came out. Having grown up in New York City in a family of artists and social workers, this process was fairly easy for me. Being gay became a central part of my identity, and I celebrated my difference. My childhood had taught me that families came in many forms. The vast majority of my high school friends had divorced parents. I had a hippie feminist mom, a father, and a stepfather, all of whom were active parents. Although I did not know any gay parents, I saw fatherhood as an option. During my sophomore year of college, I broached the subject of co-parenting with a close friend, and we agreed to consider raising a child together if she did not get married.

The Loss of Parenthood

Near my 30th birthday, I was surprised to find out that I was HIV-positive. Like many people, I fell into a depression. At the time of my diagnosis in the mid-1990s, I was an HIV social worker in the Caribbean, and protease inhibitors had just become available. Both my clients and friends were struggling with HIV or succumbing to AIDS.

From the outset, I coped by writing in a journal. One of the first losses that I identified was letting go of my dream of becoming a parent. This surprised me because I had not thought much about parenting. Yet the loss of parenthood occupied my first thoughts as I reacted to my diagnosis, rather than what I imagined to be the more common reaction—fear of disability and death.

Having a child meant a connection to the past and to the future. My mother had died, and I had hoped that a piece of her would live on in my child. The fact that I had recently broken up with a partner and felt like I was surrounded by children added to my feelings of grief and isolation. I knew I would miss the immediacy of loving and nurturing a child. But given my uncertain future, biological parenthood did not seem fair to a child—even in the unlikely event that I could find a woman who would be willing to have a child with me. I also assumed that being HIV-positive would preclude me from adoption.

There’s a Spanish expression—"If you don’t want to die, don’t be born." Although it was painful, I believed that if I let my dream of parenthood die, it would make me stronger—that part of what I was learning from HIV was about the death of some dreams and the birth of others. So I let go of my vision of fatherhood—I didn’t feel like I had a choice. I imagined that there were other ways that I could meet my need to nurture: my HIV work took on added significance, and I collected a record number of plants.

Instead of parenthood, I decided to focus on my health. Soon after my diagnosis, in 1994, I relocated to San Francisco, seeking both the best medical care and a supportive HIV community. I became involved in an underground clinical trial whose goal was HIV viral eradication through intensive HIV antiviral and immune system modulation treatment. Although it remains unlikely that I cleared the virus from my body, I have been fortunate ever since to have had a high, stable CD4+ cell count and an undetectable viral load.

Reconsidering Parenthood

Over the years that followed, as I continued to build relationships with other HIV-positive people, I regained my faith that I could become a dad. I became involved with a partner who had been HIV-positive and asymptomatic for more than 15 years, and we sometimes spoke about parenting. I met...
an HIV-positive gay man and his partner who had adopted an infant son years before; at that point, their son was completing high school. I had another HIV-positive friend who was pursuing adoption as a single dad.

At work, some of my HIV-positive heterosexual and bisexual clients were having, or considering having, children. Since many were in HIV-discordant couples, they sought information about safer ways to achieve pregnancy. Often they and their partners were struggling—trying to figure out how comfortable they were with risking unprotected sex in order to have children. To better advise them, I began to do more research on assisted reproductive technologies, including sperm washing.

A Legal Roadblock

Sperm washing is the procedure by which sperm is separated from the other components in a semen sample as the first step of a fertility intervention. At that time, and until September of 2007, the California Health and Safety Code prohibited fertility assistance institutions from accepting semen samples from HIV-positive men. In the 1980s, this law protected women from unknowingly acquiring HIV from a sperm bank sample.

By the 1990s, however, the law effectively prevented providers from using this assisted reproductive technology to reduce the likelihood of HIV transmission to HIV-negative women with HIV-positive partners and to the couples’ resulting children. This left couples with the choice of not conceiving children together or of relying on only partially effective risk reduction techniques, for example, having unprotected sex when blood viral load was low, suggesting less infectiousness, and hoping that this correlated with semen viral load, which may vary.

As a counselor working with couples, I felt my job was to help them evaluate their understanding of the information, determine their own risk tolerance, and then support them in the decisions that they made. I felt frustrated that the state’s public health policy was, in fact, increasing the risk for HIV transmission and that the majority of my clients lacked the economic resources to access out-of-state reproductive assistance.

Even if HIV was not an insurmountable obstacle, by the time I was nearing my mid-30s, the possibility of fathering my own child seemed ever more remote. I struggled with feelings of inertia. I was unsure how to find a co-parent, and in addition, like many people considering parenthood, I wondered about my ability to be a good parent. I was aware of the amount of time and dedication that it would take to raise a child. As a full-time commuting worker with a chronic disease and without a community of other parents like me, the thought of raising a child was daunting.

Although baby-making was not happening in my life, love was. By 2004, the third year of my relationship with my present partner, I felt that he could be “the one.” I broached the subject of having a child together, and, although he was not ready for that commitment, he said that he was comfortable with my pursuing fatherhood independently.

Finding a Co-Parent and Becoming a Dad

I began to propose co-parenting to a few women I knew and was surprised that none of them expressed reservations about the proposition due to my HIV status. Although none was interested in having a child, two friends offered to help me find a woman with whom to co-parent. I appreciated their offer, but it seemed incredibly unlikely that we would find someone willing to sign on for this adventure with an HIV-positive stranger.

About three months later, one of my friends told me that she had found someone. She was right. My prospective co-parent and I began to talk, and by our third meeting, I disclosed my HIV-status. Although she was concerned about HIV transmission, it was not a deal-breaker. We got to know each other slowly, meeting twice a week for a year, always sharing a meal and then discussing some aspect of child rearing. We found a therapist with personal and pro-

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fessional experience in alternative families, went into “coaching” (our term for a form of counseling focused on developing good communication and parenting skills) and eventually developed a co-parenting contract with the assistance of a lawyer specializing in alternative families. We also researched reproductive technologies extensively in order to minimize the risk of HIV transmission to her and our child.

In 2004, shortly before my 40th birthday, we decided to attempt pregnancy. At the time, the California Health and Safety Code still prevented us from using sperm washing or any other reproductive technologies, such as IVF and ICSI (described below). So I sent my sperm to a Massachusetts research institute to be “cleaned” and then shipped to a university-affiliated infertility clinic in Oregon. There, one of my cleaned sperm was injected directly into each of my co-parent’s mature eggs, which had been collected from her ovaries. The company then chose the two most viable fertilized eggs and implanted them in her uterus, procedures known as intracytoplasmic sperm injection (ICSI) and in vitro fertilization (IVF). Nine months and two weeks later, we had a healthy (nearly 10-pound) son.

I have lived with my son and his mother since before his birth, which allows us to more equally share the pleasures and responsibilities of raising him. We wanted to create a sense of home and family for ourselves and for our son, not be separated from him for days at a time. Over the past two years, my male partner has also become very close to my son, and has begun to fill a role like the one that my stepfather filled for me. We are now exploring new housing situations that will allow all four of us to live together or in very close proximity.

Few Obstacles, Much Support

Looking back, the only real discrimination that we encountered was from our insurance carriers. Medically, my HIV infection is considered a “male infertility factor,” and although we both had insurance for fertility treatments, we were denied coverage based on the insurance industry’s interpretation of the California Health and Safety Code. Even though at that time the sperm washing procedure was legal in 48 other states, our carriers would not allow us to go out of our network to receive services.

The medical establishment’s response was mainly positive. The medical director of the Bay Area Perinatal AIDS Center (BAPAC) was particularly helpful to us, both professionally and personally. Medical staff from the University of California, San Francisco and local fertility clinics were also very positive. In contrast, the medical staff in Oregon, where we had the ICSI/IVF procedure seemed distant and reserved. It was not clear if they were trying to insulate themselves from the anguish many reproductive assistance clients feel or if they were experiencing HIV-phobia or judgment about our choice to parent.

Overall, we have been extremely fortunate, and have been impressed by the support we received from our friends. Many were surprised by our purposeful, methodological approach, and I realized that we had become models for others in our circle (both gay and straight) who were considering parenthood. My decision also influenced one of my closest HIV-negative gay male friends to pursue co-parenting with a lesbian.

The hardest coming out about my HIV status was to our son’s maternal grandparents. My “out-laws,” as I call them, were not aware of my HIV status until almost two years after we met. From early on, their daughter and I had decided that it would be her decision when to tell them. Yet as time passed, that decision grew harder to live with, and I began to feel that I was being dishonest by not telling them. I also feared that when they found out they would be upset. To the contrary, when their daughter told them, they were incredibly supportive.

Fatherhood: My New Identity

Parenthood is one of the greatest achievements of my life. There is always something new, profound, common, thrilling, and, at times, overwhelming. Although I am a gay dad, very little of my life is “gay” as I once defined it. To me, being “gay” meant pursuing cultural and political activities, engaging in an active social life with other gay people, and taking adventure-filled vacations. Now, the free time necessary to engage in these activities is a thing of the past. When I am not working, I am taking care of our son. I have drifted away from some of my gay male friends in a way that is similar to the divide that sometimes separates straight people who become parents from their friends who do not.

While I sometimes feel further from my gay identity, I feel a sense of newfound
camaraderie with all dads. As a younger person, I believed that my parenting style would be much different than a straight parent’s. Yet, as we nod at each other across the playgrounds, at the zoo, or in the grocery store, I am struck by how much we have in common.

Conclusion
HIV still sometimes presents me with challenges. At times, I feel isolated. When this happens, I remember the time that one of my clients asked me if I was HIV-positive. When I asked him why it would be important for him to know my HIV status, he said, “Sometimes I feel like a zebra in a field of horses, and I want to be around other zebras—to not feel different for once.” Sometimes I feel that way too.

Related Resources

Consultation

Journal Articles

Kirshenbaum SB, Hirky AE, Correale J, et al. “Throwing the dice”: Pregnancy decision-making among HIV-positive women in four U.S. cities. Perspectives on Sexual and Reproductive Health. 2004; 36(3): 106–13. Examines the biomedical, individual, and sociocultural themes that influenced 56 HIV-positive women’s decisions about parenting. Notes that most women who stated they did not want to become pregnant after an HIV diagnosis cited the risk of vertical transmission (which was often overestimated). In addition, most women who did not desire children after diagnosis already had children.

Web Site
Bay Area Perinatal AIDS Center (BAPAC): http://php.ucsf.edu/bapac/. This site, part of the UCSF Positive Health Program at San Francisco General Hospital, offers resources and information on healthy conception and birth for HIV-positive people and their partners, as well as information for service providers on this topic.

Next Issue
Transgender people at risk for HIV face multiple barriers to prevention and care services. In the Spring 2008 issue of FOCUS, University of Minnesota Associate Professor Walter Bockting, PhD, explores the interplay between stigma, resilience, transgender identity, and HIV. Also in the Spring issue, Don Operario, PhD, Deputy Head of the Department of Social Policy and Social Work at Oxford University, examines the challenges of HIV prevention work with transgender women and men and their sexual partners.