HIV Information

General Issues

Women account for about 12% of all AIDS cases in the United States and 50% worldwide. Furthermore women are being infected at a rate greater than any other population. However, HIV is still under-diagnosed and under-researched in women. This is in part because many women in the United States are not perceived to be "at risk" and often physicians do not recognize early signs of HIV infection in women. Although treatment and care issues are similar for both men and women, certain issues concerning HIV treatment are specific to women. Guidelines for Women with HIV/AIDS will address some of these issues, including social, psychological, and physical issues of HIV and women.

Some Frequently Used Abbreviations and Terms:

- AIDS: Acquired Immune Deficiency Syndrome
- HIV: Human Immunodeficiency Virus
- IV: When a drug is administered intravenous (directly into the veins) by infusion.
- IM: When a drug is administered as an injection into a muscle.
- PO: When a drug is administered orally.
- Mx: Maintenance therapy. When you have already had an active infection and drugs are prescribed to prevent re-activation of the infection (referring to Opportunistic Infections)
- Px: Prophylaxis or preventive therapy. Usually given when people are severely immune compromised (less than 200 CD4 cells) to prevent common infections such as PCP (pneumonia). Also given when you know you have come in contact with an infection but don't yet have the infection yourself, such as tuberculosis.
- Tx: Treatment or therapy
- mg: Milligrams
- kg: Kilograms (1kg = 2.2 lbs)
- STD: Sexually transmitted disease.

For more information, please also refer to Guidelines for the Management of Opportunistic Infections and Guidelines for the Management of Gynecologic Infections or call our hotline 1-800-822-7422.

Social - Family/Friends

- Unfortunately, there is no "Guide to the Emotional Management of HIV" - no "right" or "wrong" way to tell someone you're positive. Relationships may change as people become aware of your HIV infection. Although revealing your HIV status may pose the risk of rejection by some people, "coming out" can also strengthen relationships and open the door to new ones. It is important to identify a network of family and friends with whom you can openly discuss HIV and address the unique concerns that come with the virus. At the end of this fact sheet is a list of resources including newsletters and organizations which strive to help provide such a network for women.

Partner/Lover

It is most important to inform your lover or spouse of your HIV infection, as it also has an impact on him or her. Although knowledge of your HIV status can certainly disrupt a good relationship, don't assume it will destroy one. Finding an appropriate time or method to tell your partner that you have HIV is difficult and will of course vary with each situation. It may be helpful to provide him or her with printed information to help better understand the disease, as well as information on where he or she can seek anonymous HIV testing. Perhaps seek out a support group so that you and your partner will be able to meet other couples that are sharing similar concerns regarding HIV and relationships. If you're in an abusive or threatening relationship, it would be a good idea to consult first with your local AIDS organization and battered women's center. If not currently in a relationship (but wish you were), don't assume that HIV means you can no longer give and receive love. Although sex may not be your top priority at this time, it is important to remember that sex is something which can help affirm life. Safer sex practices will be discussed later in this fact sheet.

Children

In addition to discussing HIV with your lover, you also should consider informing your children of your HIV status. Children are very perceptive and often know (although they may not have been told) that something is wrong, and may think that your illness or stress is their fault. Reassure them that they are not the cause. Honesty may be the best approach in telling your children that you have HIV, yet remember to provide information to them at an educational and developmental level they can understand. For example, a very young child won't understand that fatigue often accompanies HIV, but would accept that sometimes mom's get sick or tired and need to take naps, just like little kids. Upon learning that their mother is infected with HIV, older children often experience anger or frustration. Unfortunately, few special services are available to address their special needs. It may help to find someone, such as a social worker, family member, special teacher, or therapist with whom your children can talk freely. Acknowledge that you and your doctor do not have all the answers concerning HIV, but as you learn more you will explain more to them.

Unfortunately, many women discover their HIV status during pregnancy or when a child is diagnosed HIV+. In the case of an HIV+ child, it is even more important to be honest. A child knows if he or she is different than other children. Included in the resource list at the end of this fact sheet are some organizations which offer special services to families with HIV. Further

considerations regarding pregnancy and parenting can be found later in this fact sheet. A Pediatric HIV Fact Sheet is also available through the Project Inform Hotline.

Pregnancy, Resources, References

Pregnancy - Making Difficult Decisions

One important choice that arises with many HIV-infected women is whether or not to have a child and what (if any) intervention should be used to reduce the risk of transmission from mother-to-child. Several factors need to be considered when making these decisions or when counseling a woman who is.

In the United States, there is an average 20%-30% chance of transmitting the virus to the fetus during pregnancy, labor, or delivery.

The possibility of transmitting HIV to a child also exists through breast feeding. Therefore, HIV+ women in developed countries such as the United States are advised against breast-feeding.

If a woman's overall health is very poor or she does not receive adequate prenatal care, the risk of transmission could be much higher and possibly place an increased strain on her health.

Factors involved in perinatal transmission of HIV are not fully understood. A high level of virus in the mother's bloodstream or a deficiency in Vitamin A may predict an increased risk of mother-to-baby transmission.

Who will care for the child if mom becomes ill and can no longer do so? Some states allow joint guardianship between the parent and a future or temporary guardian. A responsible and caring mother should never feel pressured into giving up her child unwillingly or prematurely. Refusal of treatment or the decision to continue a pregnancy does not legally constitute irresponsible behavior. Local AIDS organizations can usually provide legal advice or a referral. Adoption services are included in the resource list at the end of this document.

A child can also be an important source of joy and support. A child's presence can decrease one's sense of isolation and provide some women with a reason to survive. In addition, caring for a child can increase self-esteem and often stop a parent from continuing harmful behavior, such as drug abuse.

Many medications used to treat HIV-related infections have either not been studied in pregnant women or are contraindicated for use during pregnancy. Pregnant HIV+ women should seek prenatal care with an obstetrician familiar with HIV and willing to consult with her primary care practitioner. Special Medicare guidelines expand income restrictions, allowing temporary coverage for prenatal, delivery and post-partum care for women who otherwise could not qualify. Often providers at government funded clinics are very knowledgeable in HIV and offer affordable care.

Ultimately, decisions regarding pregnancy must be made by the woman.

It has been assumed that a low CD4+ lymphocyte (T-cell) count may be a risk factor in perinatal transmission. However, more recent observations suggest otherwise. In ACTG-076, women who had around 200 CD4+ cells were no more likely to transmit than women with CD4+ counts much higher. In addition, some prenatal care providers have noticed that CD4+ counts don't indicate as much as CD4%. At time of this printing, no controlled studies have been performed to confirm these observations. A woman's immune system (regardless of HIV status) is naturally suppressed during pregnancy and then rebounds (returns to normal) after birth. It was initially feared that since an HIV+ mother's CD4+ count doesn't always rebound to the pre-pregnancy level, that pregnancy could be dangerous for positive women. However, recent studies have shown that pregnancy does not seem to adversely affect an HIV+ woman's health or cause her disease to progress more quickly.

What If Your Child Is Positive?

When a child is born, s/he will still carry the mother's HIV antibodies and therefore may test "false positive." Children usually lose their mother's antibodies by 18 months and you can usually get an accurate antibody test result after your child's 18th month. However, other lab tests (HIV culture and Polymerase Chain Reaction or PCR) can provide a diagnosis much sooner. In the unfortunate case that your baby is HIV+, he/she will require a great deal of special care.

Several factors must be considered if your baby is positive. HIV+ babies usually have a higher rate of health problems, developmental difficulties, and more severe childhood diseases. Caring for a sick child should not cause you to ignore your own health. Remember that as important as insuring your child a healthy happy life may be, it is equally important they have a healthy mom.

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