Adding in the Health Factor

Finally, comprehensive guidelines for people with hemophilia and HIV

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In each issue, POZ *publishes a different standard of care, a guide by which people with HIV and their care providers can make personal choices about health care regimes. HIV standards of care differ by region, treatment philosophy and patient population.* POZ *is proud to present the first comprehensive standard of care for people with hemophilia and HIV (abridged version), prepared especially for this issue by Richard Colvin, M.D., Ph.D. (and reviewed by Margaret Ragni, M.D., of the University of Pittsburgh) on behalf of the Committee of Ten Thousand, an advocacy group for people with hemophilia and HIV (of which Colvin is one).*

Many aspects of HIV care in people with hemophlia are identical to the standard of care for other people living with HIV, but there are several key differences. Side effects of HIV-related medications may be exacerbated, requiring closer monitoring-both clinically and through liver-function tests. And people with hemophilia must consider the impact of treatments on their blood-clotting problems, particularly in their joints and soft tissues. Some of the following recommendations are specifically for the vast majority with *severe* deficiency of factor VIII or IX. Most points, however, apply to all people with hemophilia and HIV infection.

PROCEDURE

Choice of physician

Although some hematologists have HIV expertise, people with hemophilia should seek referral to an infectious-disease specialist for at least a one-time consultation on managing HIV and hepatitis C infection.

Hepatitis monitoring and treatment

All HIV positive people with hemophilia should be tested for antibodies to hepatitis C virus (HCV) and for hepatitis B virus (HBV) surface antigen (to determine if they are chronically infected with HBV). Diagnostic evaluation for HCV includes an HCV viral RNA assay and HCV subtyping. Liver functions (AST, ALT, bilirubin, LDH) should be tested every six months. If HCV RNA is elevated, and AST and ALT enzymes are persistently elevated, consideration should be given to treating the hepatitis infection. The only current treatment is the toxic and marginally effective drug alpha-interferon; antiretroviral drugs may indirectly benefit chronic liver disease. Liver function should also be measured before and within four to six weeks after introducing any new drug metabolized by the liver. If toxicity occurs, serious

consideration should be given to seeking an alternative drug.

Choice of clotting factor

Intermediate-purity factor, often prescribed because it costs about one-fourth as much as the higher-purity factors, may transmit hepatitis C and other viruses and immune-suppressive molecules. *The use of intermediate-purity factor is not justified* (except to treat special conditions for which there is no alternative). Several studies have suggested that higher-purity clotting factor (either recombinant or monoclonal-antibody-purified factor) slows the progression of HIV disease compared to intermediate-purity factor. Recombinant factor is preferred since the monoclonal factor (about 10 percent cheaper) may carry undetectable or yet-to-be-indentified viruses.

Protease inhibitor treatment

Due to some reports of spontaneous hemorrhage in people with hemophilia taking a protease inhibitor, the FDA advises physicians to monitor their patients for spontaneous bleeding. Report any bleeding episodes suspected of being drug-related to FDA MedWatch at 800.FDA.1088. The development of kidney stones during treatment with Crixivan (indinavir), a side effect in some PWAs, poses particular problems for people with hemophilia. People with hemophilia taking Crixivan should drink at least 10 glasses of water per day and carefully monitor their urine for signs of bleeding and/or stone formation.

Pain control

Aspirin is absolutely contraindicted in people with hemophilia because it inhibits platelet function. Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, naproxen and ketaprofen should be used cautiously, and in some, not regularly, since they can also inhibit platelet function (although not as seriously as aspirin) and many cause stomach bleeding. When NSAIDs are co-administered with AZT, particular attention should be paid to possible bleeding episodes. The combination of AZT and ibuprofen causes increased incidence of serious bleeding episodes in people with hemophilia, particularly those with ulcer disease or thrombocytopenia. Pain may be more safely controlled with acetaminophen (contained in Tylenol). But people with liver disease should minimize or avoid use of acetaminophen unless there are no alternatives (consult physician).

Invasive diagnostic procedures

To avoid complications from bleeding, people with sever hemophilia may want to infuse clotting factor prophylactically, prior to undergoing such invasive diagnostic procedures as arterial blood-gas aquisition, lumbar puncture (spinal tap), bronchoscopy, endoscopy, liver and kidney biopsies, and such dental procedures as teeth-cleaning and Novacaine injection. For PCP monitoring, pulse oximetry can often substitute for blood-gas aquisition. With dental procedures, Amicar can often be used.

Treatment of thrombocytopenia (low platelet count)

When platelet counts fall below 50,000/mcl, people with severe hemophilia should prophylactically infuse clotting factor three times per week. Treatment with steroids-which are immune-suppressive-is not considered first-line therapy for HIV positive people, except for short-term use. IVIG therapy may be beneficial; antiretroviral drugs are often the most effective treatments for thrombocytopenia.

Orthopedics

Many orthopedists refuse these procedures to HIV positive people, fearing risks to the patient (weak evidence) and to themselves (no evidence). Increased monitoring during and after surgery may help reduce complications. If your orthopedist won't operate, seek a referral to one who will.

For more information, call the Committee of Ten Thousand at 800.488.COTT. The full text of this document, including guidelines on financial counseling and psychosocial care, is available on the POZ *website at http://www.poz.com.*

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