Liver Worst

Once neglected, hepatitis C finally has PWAs talking, testing and treating

September 1, 1998 By Bob Roehr

Jeff Jones lives in San Francisco and for years considered himself “very well informed about HIV.” Yet he didn’t know that the hepatitis C virus (HCV) even existed until last year when his liver began to ache with the added stress of a protease inhibitor. That’s when his doctor finally tested him for hepatitis C: He came up positive.

Lillian Thiemann knew she had HCV but “was preoccupied and distracted by my AIDS, so it was easy to forget about my hepatitis C.” The New Yorker’s liver enzymes crept up as that organ swelled with inflammation. Finally, the lethargy and pain became too much to deny. “I realized that just because I was HIV positive, it didn’t mean I had an exemption from other diseases.”

A member of the family of liver-damaging hepatitis viruses (see "Family Tree“), hepatitis C is a giant, silent epidemic -- all the more worrisome because, unlike its widespread A and B siblings, HCV can’t be prevented with a vaccine. An estimated four million Americans are infected -- more than four times the figure for HIV. It’s the leading reason for liver transplants, and its complications kill an estimated 8,000 to 10,000 people a year. Hep C infections surged in the 1960s and 1970s through contaminated blood transfusions, clotting factor and other blood products -- a disaster that hemophilia activists say resulted from a negligent failure by blood-product manufacturers to screen donors and develop viral-inactivation technologies. HCV screening of blood, initiated in 1990, has all but shut down that transmission route, but needle-sharing by injection drug-users and other paths remain (see ”Blood Lines"). Although new infections seem to be declining, more people are getting sick from old infections. Some experts say the death rate could double in the coming decade.

Among people with HIV nationwide, the rate of HCV co-infection varies by group: Estimates are less than 10 percent among gay men (but much higher in specific locations), 80 percent to 90 percent among those who have injected drugs and nearly 100 percent among people with hemophilia who used blood factor products prior to screening. Yet most PWAs have no idea that they may be coping with two viruses.

Until recently, conventional medicine had little to offer those with HCV. Like HIV, it is a virus that mutates easily, making it tough to fashion a therapy or preventive vaccine. But HCV’s secrets are being unlocked, and the pace of progress is accelerating. The standard single-drug treatment --

with limited results at best -- has given way to combination therapy. And alternative therapies offer additional hope.

According to the Centers for Disease Control and Prevention (CDC), about 15 percent of people infected with HCV throw it off within six months; the rest develop chronic hepatitis. Of these, 20 percent to 30 percent will ultimately develop cirrhosis (liver scarring), liver failure or cancer. But you might not see symptoms for 20 years or more, says Jerry Powell, MD, professor of hematology at the University of California, Davis. “The liver is a smart organ,” he says. “You can be asymptomatic with only 10 percent of it left working.” Once symptoms arrive, they can include extreme fatigue, aches, nausea, pale stools, jaundice and kidney problems.

Until recently, the combination of HCV’s tortoise-like progression and mediocre treatment meant that many physicians did not even look for it. And consumers weren’t educated to demand screening. But that’s changing with a new public education campaign by the feds and nonprofits on the risks of hep C and the importance of knowing your status.

Who should get tested for HCV? Anyone who has ever had any risk of exposure, no matter how long ago. The virus can be detected in blood within one to three weeks of exposure. The basic antibody test misses some 20 percent to 50 percent of infections in co-infected people, so ask for the new viral load (PCR -- polymerase chain reaction) test, which -- as with HIV -- measures the virus, not the antibody. PCRs may also prove to be good tools for monitoring treatment effectiveness, along with liver enzyme tests (rough but imperfect measures of liver inflammation).

Howard Grossman, a New York City physician with a large HIV practice of primarily gay men, tests “everybody who comes through the door” for hepatitis A, B and C. “If they haven’t been exposed, we vaccinate [for A and B].” Until recently, he says, such screening was not the standard of care for most physicians, partly because “we had to fight the managed care companies to do that.” But he says hat the bean counters’ attitudes are changing. Douglas Dieterich, MD, professor of medicine at New York University and a leading researcher and clinician of co-infected people, urges PWAs to be aggressive in demanding screening and vaccination from their doctors. He notes that a recent Italian study (of HIV negative people) found that hepatitis A, normally not a life-threatening disease, killed about 40 percent of people already infected with HCV.

Do people co-infected with HIV and HCV progress more rapidly to advanced stages of HIV disease? Expert opinion is split. A few studies have foundThomas, MD, a hepatitis researcher at Johns Hopkins University, says that while the co-infected progress more rapidly to liver disease than do HIV negative people, he remains unconvinced that HCV infection promotes HIV progression. Grossman concurs but notes, “People in my practice with underlying liver disease may get side effects from some medications a little faster.”

Because some HCV positive people may never develop symptoms, the National Institutes of Health (NIH) only definitively recommend treatment for those with both detectable HCV levels and elevated liver enzymes.

For several years, the only FDA-approved treatment for hepatitis C was alpha interferon (brand

names Intron A, Roferon-A and Insergen). This injectable drug works as an immune modulator that "seems to help teach the immune system how to react to hep C," Dieterich says. The standard protocol calls for three-million-unit injections three times a week for up to a full year. Studies of those with HCV alone have found that only about 20 percent of the patients on alpha interferon see sustained suppression of their viral load. The numbers are higher at first, but the virus often rebounds when interferon is stopped. (However, one study suggests that gradually going off interferon may reduce the risk of relapse.) NIH recommends changing or discontinuing treatment if no benefits are seen within three months.

But many experienced clinicians think the approved protocol for interferon is suboptimal. The kidneys quickly filter out the drug, so Powell recommends daily injections of at least five million units. Clinicians have also found that effective dosing may be weight-related, but there is not yet a table to calculate such dosing.

Todd Smith, a Palo Alto, California PWA with hemophilia is living proof that the high-dose approach can work. In 1994, with his hepatitis C flaring up and his liver enzymes rising, he went for interferon treatment. When the approved dosing didn't help, his doctor upped the quantity to five million units and the frequency to every day. That's when the magic began to happen. Smith's elevated liver enzymes fell to the normal range, and his hep C viral load declined, though it never disappeared.

"I stopped it after about a year and a half," Smith says, "because the side effects started creeping up on me" -- in his case, thinning hair and morning nausea. But two years later, his liver enzymes are still in the normal range. Interferon's adverse effects are no picnic: Most people will see a major drop in red blood cells (anemia), white blood cells or platelets, especially if taking HIV drugs with a similar side effect. (For that reason, frequent blood monitoring tests are important.) Interferon takers with a history of autoimmune disease may experience reactivation or worsening of symptoms, while severe depression may occur. But the most widespread side effect of interferon is flu-like symptoms, which some PWAs call the "flu from hell that never goes away." Injecting the drug before bedtime may reduce these side effects.

Interferon does little good when the liver is significantly scarred, and scarring can only be detected by a liver biopsy. The procedure involves inserting a hollow needle into the liver to take a tissue sample. "I was scared to death of the biopsy," says PWA Jeff Jones. But his liver was sore and swollen and he was exhausted from fighting HIV. Jones says, "Finally, my doctor got me to understand that it would provide information not just about my liver, or my hepatitis C, but about which therapies I could tolerate." Jones demanded, and got, adequate painkillers. (Since then, a new, less painful biopsy technique, called trans-jugular, has become available in some areas; it threads a catheter through the jugular vein in your neck and down into your liver to take the tissue sample.) Jones' biopsy showed significant liver scarring, so he was not a good candidate for interferon, but he used the information to change his HIV meds.

A new era in hep C treatment has just begun with FDA approval of combination therapy (called Rebetron) with interferon alpha-2b (Intron A) and ribavirin (Rebetol), both manufactured by

Schering-Plough. Ribavirin is a nucleoside analogue (the same class as AZT) developed in the late 1980s. Back then it showed test-tube activity against HIV -- which led PWAs to smuggle the drug in from Mexico. While many reported ribavirin helped them, studies in humans failed to show clear benefits. And when used alone against HCV, the drug had poor results. But clinical trials in HIV negative people with hep C found that the combination of ribavirin and interferon produced sustained suppression of HCV for two to three times as many as did interferon alone. And up to 60 percent on the combo sustained HCV suppression off therapy. A clinical trial is underway to see if similar benefits occur in co-infected people, as anecdotal reports suggest.

The combination, however, has several downsides: In trials to date, it only worked in half those taking it. And besides the usual interferon side effects, ribavirin may produce severe anemia that can lead to a heart attack or stroke in people with risk factors; psychiatric problems have also been reported. Plus the combo's price tag is steep: $6,400 to $8,600 a year, depending on dosage. (The PWA Health Group, a New York City buyers club, sells ribavirin at a greatly discounted price.)

Other treatments are in the pipeline, now that the genetic structure of HCV has been mapped. Adopting the computer modeling techniques used so successfully by anti-HIV drug designers, two pharmaceutical companies have developed potential protease inhibitor drugs for HCV. Human trials are still several years away. The limited effectiveness of medical therapies for hepatitis C has sparked wider interest in nutritional supplements and herbs among people with the virus. The alternative treatments seem to help detoxify the liver or modulate an immune response, rather than directly attack HCV.

Clinical experience of hundreds of patients, along with test-tube data, support the theories that dandelion and artichoke encourage the flow of bile from the liver; glycyrrhizin (licorice root extract -- an approved hepatitis drug in Japan) quells inflammatory processes; and silymarin (milk thistle extract) promotes liver regeneration.

An antioxidant widely reported to help treat HCV (as well as HIV) is N-acetyl-cysteine (NAC), which boosts levels of glutathione -- a key nutrient depleted by liver stress (see "Power Nutrients," *POZ*, July 1998). One study of 24 HCV positive people (none co-infected with HIV) found that after six months of combined NAC/interferon treatment, 41 percent of those previously unresponsive to interferon had normalized liver enzymes. Nutrition experts say that combining NAC with other glutathione-builders -- including the amino acid glutamine and antioxidants such as alpha-lipoic acid and vitamins C and E -- makes a powerful liver detox cocktail.

PWAs with HCV are also turning to Chinese herbs. Hepatitis epidemics have battered China for decades, and trials there of various herbal combinations have found benefits exceeding those of interferon. Jin Lin Wang, MD, a Beverly Hills, California, acupuncturist and researcher who has treated co-infected people, says a 12-herb combo he designed has produced dramatic drops in the HCV viral loads of several patients. (He is now raising funds for a clinical trial.)

One nutrient, however, can actually cause problems. Iron build-up in the liver can make it even harder to fight all forms of hepatitis and to metabolize many drugs. Make sure that your doctor

includes a test for iron levels as part of your standard blood work. If your iron is high, it is generally recommended that you change multivitamin/mineral supplements to ones without iron. The most common treatment for the condition is an old-fashioned remedy: Bleeding (phlebotomy). It's similar to donating blood. The process forces your body to draw down liver iron to help make new blood.

Beyond specific therapies, lifestyle changes are the first order of business when you learn you have HCV. "Alcohol ingestion clearly worsens the course of hepatitis C," noted a 1997 NIH consensus report. So experts recommend laying off liquor.

Drugs metabolized in the liver can stress an organ already challenged by hepatitis. The list of these medications is huge, ranging from acetaminophen (Tylenol) to anti-HIV drugs, including all of the protease inhibitors and non-nucleoside reverse transcriptase inhibitors (NNRTIs).

"I feel like I'm walking a tightrope," Todd Smith says. He protects his liver by choosing the low end of dosing options for all medications that affect it. He advises reviewing all treatments with your doctor for their effect on the liver. Jeff Jones had to stop taking saquinavir (Fortovase) when his liver flared up. Both also switched to low-fat diets, which are less liver-stressing.

And simple measures like drinking plenty of water, avoiding chemical fumes, taking steam baths or saunas and getting plenty of rest can all make a difference in minimizing wear and tear on the liver. Lillian Thiemann says she combined "dietary adjustments, herbs, vitamins, acupuncture and clean living" to treat her hep C. "It was very satisfying to get my liver enzyme levels to within normal range, which allowed me to enroll in a clinical trial for an anti-HIV drug."

Thiemann's experience with co-infection helped inspire her to become a treatment educator. "Separately, HIV and HCV can be tough adversaries," she says. "Together, they used to seem unbeatable. But by learning about all the tools available and choosing those that work for me, I've given myself a fighting chance. Now I tell anyone coping with these two viruses: You, too, can beat the odds! Just don't wait till your liver screams."

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