Power Plants

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A key ingredient in my decision-making about treatments is how they make me feel," Hal Kooden says. "*Side effects* is a term that trivializes the negative effects of antivirals." That's why the 61-year-old New Yorker has eschewed antiretrovirals in favor of alternative treatments since testing positive in 1989. Herbs top the list. "Every day I take bitter melon and SPV-30 [boxwood extract] as antivirals and cat's claw for immune enhancement. To balance the immune system, I also alternate three weeks of Siberian ginseng with one week of astragalus." Kooden also gets weekly acupuncture and uses a gaggle of vitamins, minerals and amino acids, along with judiciously chosen pharmaceuticals: Acyclovir (Zovirax) for herpes prophylaxis, naltrexone to stabilize immune function, and Tagamet as an antacid.

Kooden credits the total mix for his undetectable viral load, 400-ish CD4 count and overall good health, but adds, "I'm acutely aware of what affects my body. The herbs I use make me feel better."

Pre-protease surveys -- the only ones available -- found that about 20 percent of Americans with HIV were using herbal medicine as part of their regimen. Now buyers clubs and PWA groups report reduced usage. But among PWAs worldwide -- an estimated 80 percent have no access to expensive medications -- herbs are likely to remain the treatment of choice, drawing on centuries of cultural experience with medicinal plants. With many PWAs like Kooden betting their lives on herbs, the question arises: What's the proof that herbs safely and effectively treat HIV and the numerous problems it spawns?

Try the growing number of reports from doctors. "Herbs are less toxic than conventional therapies for certain AIDS-related conditions such as anemia and hepatitis," says Rick Elion, MD, who has a large HIV practice in Washington, DC and is trained in Chinese herbal medicine. "And herbs make patients feel better overall, which is something I didn't appreciate at first because I was interested in herbs only as drugs to treat specific ailments," he says.

Alan Berkman, MD, medical director of a long-term AIDS care facility in New York City, believes that physician interest is likely to grow. "As HIV becomes more of a chronic illness, something Western medicine has difficulty dealing with, herbs become important because they are often better than drugs for treating chronic conditions such as diarrhea or muscle pain," Berkman says.

Some PWAs are passionate about the benefits of herbs, ranging from the antiviral and immunomodulating effects of glycyrrhizin to the anti-infection action of allicin to the liver-

detoxifying properties of silymarin (for info on choosing and using specific herbs, see "Plant Primer"). "Bitter melon has saved my life," says Stanley Rebultan of Los Angeles, 46, who has never used drug therapies and has taken the herbal extract by rectal enema since 1989. "In the two years before I started taking it, I frequently got colds and minor infections and had my T-cells drop from 640 to 480. Now, I never get sick and my T-cells fluctuate between 800 and 1000," he says, adding that he has an insignificant viral load.

While patient and doctor anecdotes are important puzzle pieces, the clinical research data is still largely missing. Yet that is crucial to confirm which product helps which condition -- and to obtain the medical establishment imprimatur vital to insurance reimbursement. The general absence of data has stoked controversies about safety, effectiveness and appropriate use.

For example, all but the most strident advocates grant that people with advanced HIV should use antiretrovirals. At the same time, most herb-endorsing doctors would feel comfortable with patients in an early infection stage waiting before starting a cocktail. Their point of divergence is this: Will herbs alone suffice in that gray area between high CD4 counts/no symptoms and low CD4 counts/ opportunistic infections -- and for how long?

"It's hard to say who is going to respond to herbal therapy," says Fred Bingham, a long-term survivor who has used herbs for years. "With alternative treatments, there isn't a set of laws that can be applied with absolute certainty. People have to experiment." But based on his observations as founder of Direct AIDS Alternative Information Resources (DAAIR), a nonprofit buyers club, he says the best candidates to try an herbs-only approach are those with fewer than 20,000 viral copies and a stable CD4 count above 150 for six months to a year.

Like their pharmaceutical counterparts, herbs may offer more anti-HIV punch when used in combination. Bingham says that a few DAAIR members have gotten modest benefits from a mix of glycyrrhizin, curcumin, bitter melon and SPV-30 -- all of which inhibit test-tube HIV. "Twenty to thirty percent of people with HIV could have a very low viral load and extremely slow progression of disease on combination herbal therapy alone," Bingham says.

But Don Brown, a naturopathic (natural medicine) doctor and author of *Herbal Prescriptions for Better Health* (Prima Publishing/Rocklin, California), rejects the exclusive use of herbs to fight HIV. "At best, herbal therapy is an adjunctive treatment," he says. "Research is needed to prove herbs are potent enough to be a primary medicine."

Elion keeps an open mind. "Let's say I had a patient with 530 T-cells and a viral load of 20,000. If the patient was fully willing to commit, I'd probably recommend antiretroviral drugs -- or a drug-herb combo -- because viral load could rise and immune response could decay. But I could also support just using herbs, antioxidants and nutrients, and accurately say that they are less toxic, will support the immune system, avoid resistance and allow a greater choice of drugs later," Elion says. "We need to provide as much data as possible and let the patient make an informed choice."

Part of that "informed choice" is looking at herbs' potential for both good and ill. As natural products, herbs have a time-honored rep as kinder and gentler than drugs. But it's well-

documented that many plants can produce side effects. Alas, specific safety info on herb use by people with HIV is scant.

Take echinacea. Popular as a remedy for cold and flu, echinacea is used by PWAs to stimulate the immune system. However, author-physician Brown notes that echinacea may raise tumor necrosis factor-alpha (TNF). “TNF is already abnormally elevated in PWAs and can contribute to viral activation,” says Brown, who observes that the German government now includes such a warning in its official herb literature.

But one echinacea researcher disagrees. The herb’s effect on TNF is “minor,” according to Darryl See, MD, an assistant clinical professor of infectious diseases at the University of California, Irvine College of Medicine. See is currently running a nine-month, 60-person clinical trial of the herb to evaluate its effect on viral load and immune function.

So echinacea is OK by See, but he has a warning about cat’s claw, or *uña de gato*, an herb from the bark and root of a Peruvian plant. “Even at very low amounts,” cat’s claw kills white blood cells in the lab, See says. “We advise that patients do not use it until further studies are done.”

Drug-herb interactions are also a concern. “We know that herbs contain alkaloids, which are processed in the liver, as are protease inhibitors. But we don’t know if herbs diminish effectiveness of these drugs as a result,” says herb-supporter Charles Steinberg, MD, of the Beacon HIV clinic at Boulder (Colorado) Community Hospital.

And with the industry producing increasingly powerful products -- dubbed “herbaceuticals” by Michael Onstott, a PWA and Guerneville, California activist -- another unknown for PWAs relates to the concentration factor. “For example, the active ingredient in ginkgo biloba might be concentrated 50 times higher than it naturally occurs.” While Onstott considers long-term use of such products “a worthy experiment for people with HIV,” he asks, “What are the health ramifications?”

Thorough research could resolve many of these debates and calm anxieties. A handful of small studies now under way with PWAs -- three examining Chinese herbal formulas for diarrhea, anemia and HIV itself; one looking at the safety and drug interactions of marijuana taken with protease inhibitors -- may provide helpful data.

But the fact remains that HIV-related herbal research is largely a nonevent in the United States. Why? Money. “Herbs are products of nature. You can’t patent anything from nature,” says Ara DerMarderosian, PhD, of the Philadelphia College of Pharmacy and Science. With no promise of 17 years of patent-guaranteed big bucks, no drug company is willing to finance the costly process leading to FDA approval. “However, you can patent a derivative, which is a modification of the original molecule of the active constituent of an herb,” DerMarderosian adds. Although an estimated 25 percent of prescription drugs are derived from plants, an herb isn’t the same after the lab coats get their hands on it. Effectiveness may be reduced (or increased) and side effects intensified. Take marijuana: Many PWAs complain that its synthetic version, Marinol, is not as effective as the real thing for appetite stimulation.

Community-based research programs have done small studies on herbs (such as curcumin and allicin), and their findings have influenced many PWAs. But such organizations are hampered by a severe lack of resources.

With no deep pockets at hand, many herbal researchers look to Uncle Sam. “The government needs to fund research. The AIDS Clinical Trial Group could run nested studies, in which herbs are used adjunctively with a drug by a small cohort within a larger drug trial. That would definitely be a start,” says Fred Schaich, a PWA and executive director of the International Foundation for Alternative Research on AIDS in Portland, Oregon. He also notes that the modestly budgeted NIH Office of Alternative Medicine is the only government agency that funds herb research. “Just imagine trying to evaluate all the alternative treatments for all the diseases with one small office!” he says.

A 1995 ACT UP pressure campaign led an NIH advisory panel to recommend that the institutes’ AIDS program “provide supplemental funding” for that small office to do HIV studies, but the proposal has languished. Now AIDS researchers at UCSF and Bastyr University in Seattle are pursuing their own proposals to expand federally funded herb research. Another innovative idea being pursued by activists is asking pharmaceutical companies to fund nested studies of herbs that alleviate side effects -- and therefore extend the time a drug can be tolerated -- within trials of their products.

With research slow and herb use steady, PWAs as consumers need protections. But many alternative medicine advocates charge that the FDA has waged a four-decade war -- complete with armed raids, lawsuits and public disparagement -- against supplement manufacturers, while failing to implement the most elementary good-manufacturing rules. FDA threats in 1993 to remove whole classes of herbs from the market resulted in a massive public outcry, leading to passage of the 1994 Dietary Supplement Health and Education Act. The compromise legislation places supplements in a “regulatory Twilight Zone,” according to Mark Blumenthal of the American Botanical Council. Disease-treating claims are sharply restricted, and the FDA can yank dangerous products off the market. But herbs are not required to be government-evaluated for quality, effectiveness or safety; side effects and drug interactions do not have to appear on the label.

Because the marketplace is not usefully regulated, the burden of finding a quality product falls on the consumer. An investigation in the November 1995 *Consumer Reports* found that potency and purity of herbs varies widely. “Herbs need to be defined as products,” says advocate Schaich. “The active ingredients of herbs and their quantities need to be standardized so you can count on the effect.” Blumenthal and others call for a regulatory structure that is less rigid and costly than the one for drugs, but still protects public safety.

The future of herb usage among PWAs will in part depend on the effectiveness of drugs, Schaich says. “When drugs are down, alternative treatments and herbs go up.” Growing numbers of health practitioners say that no matter what else is going on, herbs have a special role to play in the future of HIV. But whether herbs are “up,” “down” or playing special roles, PWAs still have to make treatment choices. And decision making about herbal medicine can become the kind of well-

informed process that PWAs use with pharmaceuticals only when more research and more regulation of the industry occur.

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