The Doctor Is Out

Managed care is making AIDS docs close up shop, but some MDs are fighting mad. Plus: How to work your HMO (an Rx for patient patients)

May 1, 2002 By David Tuller

David Feiler was in a tailspin. In 1997, he was suffering severe side effects from his new protease inhibitor combination -- sudden drops in blood pressure, severe dizzy spells, extreme fatigue. “I was almost a vegetable and I stopped working,” says Feiler, who at the time owned a travel agency south of San Francisco. “That’s when I decided to take a drug holiday.”

The break -- a then-controversial move made with his doctor’s support -- boosted his health. That was the good news. But soon his physician, who was part of a medical group suffering financial pressures, delivered the bad news: She was quitting private practice to take a job with the state prison system. Feiler had already heard rumblings that some medical professionals were frustrated with dealing with insurers and exhausted from overwork. But the news stunned him anyway.

“The relationship with your doctor, especially if you have HIV, is very personal,” he says. “You become very dependent, because they are managing to keep you alive. When they just walk out on you, it’s as if you lost a family member -- or a divorce without alimony and child support.”

Feiler ultimately found another physician he liked. But his situation -- losing a doctor due to financial stress -- is one confronting more and more HIVers, particularly those with private health insurance. While some physicians retire because of age or switch jobs for personal reasons, many who have quit their private practices lay the blame squarely on one overriding factor: managed care.

Managed-care plans, whether through private health insurance or Medicaid, require members to select a primary-care physician who oversees all their treatment and refers them to specialists when necessary. Health-maintenance organizations (HMOs), the most common type of managed-care plan, pay the primary-care doc or the physician’s medical group a flat monthly fee -- called a capitation rate -- for each patient, no matter how much care is provided. Depending upon the contract, the fee may cover not only office visits but lab tests, other procedures and services, even medications. The system operates most equitably when a practice has plenty of healthy patients on whom the doctor makes a profit, a setup that helps cover the costs of treating a smaller number of the seriously or chronically ill.

Getting doctors of all stripes to complain about the time-consuming bureaucracy and paperwork of managed-care plans is easy. But for those with large AIDS practices, managed care is increasingly not just an administrative hassle but a road to financial disaster. Some physicians, like Feiler's, have chosen to leave private practice altogether. Others simply refuse to take on new HIV patients. Many have decided to sever contracts with HMOs, which sometimes pay as little as $10 or $20 per patient per month. This predicament may make AIDS as anathema to medical students in 2005 as it was in 1985.

National statistics are hard to come by, but the fate of San Francisco -- known from the first as the model in AIDS care -- is telling. In the past few years, about half a dozen physicians out of 25 or 30 recognized as experts in treating HIV have closed their practices. And some doctors with heavy HIV patient rosters say they have watched their incomes decline by as much as 50 percent, from somewhat less than the national MD median of about $160,000 to $80,000 or $90,000.

"HIV tends to highlight all the challenges of our health care system," says Christine Lubinski, director of the HIV Medicine Association (HIVMA), an organization of more than 2,000 HIV doctors that promotes access to quality care and was created under the auspices of the Infectious Disease Society of America. "If all you need is an annual checkup, everything is great. But the patients who have problems with managed care are those with complex conditions that insurers don't want to pay for. So the concern is that experienced private practitioners who continue to get $13.50 a visit will get out of the business of providing HIV care."

Treating HIV -- the ultimate "complex condition" -- has always been an extremely pricey proposition. Ironically, the financial crisis has deepened as the health outlook for people with HIV has improved. Since the advent of protease inhibitors six years ago, health care professionals say that the availability of so many HIV medications in even more combinations has vastly multiplied the complexity of managing the disease. The need for regular blood tests and office visits as well as phone calls to renew prescriptions, monitor side effects and discuss treatment strategy can sometimes boost monthly expenses to $1,000-plus, and that doesn't include the drugs.

"If someone walks into my office during allergy season, it doesn't take me long to say, 'Here's some Claritin,'" says Jerry Cade, MD, a family-practice doctor in Las Vegas. "If you have diabetes, you've got to use insulin. You don't have 16 drugs with multiple combinations. You have to think how they interact not only with the body but also with each other. You need to talk to the patients about compliance, resistance, side effects. There are just a lot more issues."

According to figures cited by the American Academy of HIV Medicine (AAHIVM), a Los Angeles-based advocacy organization for HIV doctors, HIVers tend to make six to nine times as many annual office visits as people without HIV. The organization estimates that HMO payments to medical groups are commonly about $70 or $80 per patient per month -- only a quarter to a third of what it actually costs to treat the average HIVer; drugs average $680 a month compared to $19 for a non-HIV patient.

The problem is compounded by the fact that HMOs tier their compensation levels according to

medical specialty. When a patient with cancer is referred for consultation to an oncologist, HMOs pay the consulting specialist a higher rate than the primary-care doctor. But many patients with HIV rely on their regular physicians -- usually internists or family-care practitioners -- for the lion's share of their medical needs. And that means your doctor likely receives from HMOs the same amount for treating you as for treating your buddy who comes in once a year for a physical and a flu shot.

"It's a huge issue in virtually every state we've worked in," says Dr. Julia Hidalgo, president of Positive Outcomes, a Maryland-based consulting firm that specializes in the economics of AIDS care. "Doctors may be reluctant to be listed in insurance-plan information as HIV experts because they're worried about drawing lots of patients for whom they won't get adequately reimbursed."

Even doctors whose patients are members of preferred-provider organizations (PPOs) are at a disadvantage. Unlike HMOs, PPOs pay for each office appointment and medical procedure, but at highly discounted rates -- far below the generous reimbursement of fee-for-service plans that most people with private insurance had until the 1990s. But like HMOs, PPOs often reimburse doctors the same amount for a standard office visit with a healthy person as for a longer appointment with someone chronically ill.

The disparities matter less for doctors with only a handful of HIV patients, since they can compensate for the economic shortfall with patients who require relatively few services. But in cities with large numbers of HIVers, such as San Francisco, New York and Miami, many physicians, not least gay and lesbian ones, have developed large AIDS practices. And, not surprisingly, when doctors gain a reputation for experience and skill in treating people with HIV, their pool of such patients grows rapidly. "HIV is different from other diseases because it clusters in epicenter cities, and the patients are clustered among a small number of doctors," says Stephen Becker, MD, a leading HIV doctor in San Francisco, who estimates that he has recently picked up 100 new patients from retiring doctors.

In fact, Becker's own longtime partner will soon depart. One of her patients is already fretting. "It's a really comfortable relationship," says Sam, who has had HIV for 20 years. "I love her. She's warm, like the total Earth Mother. She puts her foot down if she thinks you're doing something wrong, but she's receptive to input." He sighs deeply. "It's stressful enough having HIV. But now I feel anxiety and concern about finding a new doctor I like."

Al, another longtime San Francisco AIDS survivor, found himself in a similar situation. His doctor, who offered alternative as well as traditional treatment approaches, closed his financially strapped practice. "I took action quickly, but there were lots of other people who weren't as fortunate," says Al, who heard that some of his former doctor's patients have died since the doors were shuttered. "He saw the sickest patients, and he was keeping them alive."

Al moved with the practice's physician's assistant to another medical office, and though generally satisfied, he misses the comprehensive services his former doctor offered, such as on-site acupuncture and nutritional counseling. "They were treating me in a way that would raise my level

of health to a place where HIV could not affect me as much as it had in the past," Al says.

So far, the medical and health care establishments have taken only minimal steps to grapple with the problem. A few states, most notably New York and Maryland, are addressing the economic disparities of HIV care by developing higher capitation rates in Medicaid HMOs. Maryland's Medicaid program, for example, now pays close to $2,000 a month for each HIVer -- four or five times what it pays for the average healthy Medicaid recipient. New York's Medicaid program has not only developed higher payments for people with HIV but is creating special medical clinics for HIV care.

But short of a wholesale restructuring of the health-care delivery system, many HIV doctors and other advocates say that the best Band-Aid for the current crisis would be to implement a formal process to credential HIV specialists. Not only would an HIV specialty insure patients access to knowledgeable health-care providers, but physicians would have more leverage to demand better reimbursement. While AAHIVM and HIVMA have aggressively promoted such efforts, most private health insurers predictably oppose them.

California is pioneering the "specialty" solution. Two years ago, the state passed a law mandating that every managed-care plan have a qualified HIV specialist. The legislation, however, failed to spell out criteria for specialization, leading to complaints from advocates that health plans were ignoring the requirement. Now, at the request of Gov. Gray Davis and in coordination with AAHIVM, the state is putting the finishing touches on the guidelines for specialization. These contentious regs, effective in July, allow managed-care plans to designate as an HIV specialist any doctor who has treated at least 20 HIV patients in the past two years, taken relevant classes and passed credentializing exams.

Advocates applaud the plan for boosting the bargaining muscle of physicians devoted to HIV care. "Anything that promotes the use of HIV experience is an excellent thing," says Hidalgo, the consultant in HIV financial issues. "I certainly hope it will help other states adopt similar policies."

Taking such policies nationwide, however, will require mobilizing not only doctors but patients -- neither of whom has much extra time or energy. But without political pressure, HMOs are certain to KO the MDs. And as the best and the brightest HIV docs increasingly close up shop, the quality of patient care will plummet. The other shoe will drop when fresh troops hesitate to replace the front-line stalwarts. "Most doctors doing this work are an older cohort, closer to retirement," says Stephen Becker. "I'm 53 and I don't have plans to retire, but there just aren't many younger doctors going into the field. They see that the financial future is so bleak."

HMO'S & HIV

The news about HMOs is always a downer. The claims you file routinely get rejected or "lost." The amount you have to pay out of pocket for drugs or treatments keeps going up. Or you finally find a doctor you love only to have her drop out of your insurance plan's network or, squeezed by paltry HMO compensation, drop out of sight altogether.

HIVers typically have it extra bad because HMOs try their best not to pay for all the care and meds you need. It can take weeks, even months, for a health insurance company to start bankrolling your new HAART combo. And, as the case of HIVer Belynda Dunn shows, HMOs often go to great lengths to deny lifesaving experimental treatments (Dunnneeded -- and got -- a liver transplant).

But many docs and insurance experts say that with enough persistence and savvy, you *can*get the services you need -- and deserve. It may take a bigger battle than you ever imagined, but dig in and don't let the petty and tricky red tape faze you. Jacques Chambers, who headed the benefits program at AIDS Project Los Angeles, says, "It may take some doing, but with enough hard work, you can get most of the care you need."

Know Your Rights

In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA), an incredibly complicated law that made it easier for anyone with a pre-existing condition like HIV to get coverage. Suppose you suddenly leave your job and want to buy health insurance. If you had insurance for at least 18 months at your old job,then no insurer can deny you coverage or charge you a higher premium because of your serostatus. The same is true if you were on Medicaid or Medicare and then become self-employed. Unfortunately, if you didn't have health coverage for 18 months, all bets are off. For more about buying health insurance, click on www.ehealthinsurance.com. The site lets you compare the costs of the plans available to the self-employed in your area.

What if you come off Medicare or Medicaid and get a job? Some employers offer policies that make you wait from 3 to 18 months before you get coverage if you have a pre-existing condition. This can be a major bummer, but there's a way around it: Use your time on Medicare or Medicaid as credit. So, if your employer forces you to wait six months before you're eligible for the company's health-care plan, and you were on Medicaid for two months, you will get out of jail in -- duh! -- four months. For a fuller explanation of your rights under HIPAA, click on www.hcfa.gov/medicaid/hipaa or call 800.633.4227.

Dial-a-Doc

A primary-care doctor who knows the ins and outs of HMOs is an expert and advocate you can consult when your health insurance company starts hassling you. These days, many docs have assistants that do nothing but deal with managed-care messes. If you make nice, they'll make calls.

As if there was any doubt, a recent study showed that the more HIV experience your doctor has, the longer you live! That's one reason HIV doctors and patients are mobilizing for a fully credentialed AIDS specialty (see "The Doctor is Out" above). AIDS specialists will be better able to prevent, diagnose and treat the rich array of ills bedeviling HIVers -- not simply prescribing sophisticated meds but distinguishing depression from low testosterone from anemia from... The American Academy of HIV Medicine (AAHIVM), which is spearheading the"specialist" cause, maintains a list of accredited AIDS specialists on its website. Click on www.aahivm.org/new/index.html, or call 866.241.9601.

But given the fierce financial Catch-22 many dedicated HIV docs face in the age of managed care, Dr. Dreamboat may no longer be accepting new patients. Another good source of physician leads is your local AIDS service organization (ASO), which is likely tapped into the local grapevine of who's good *and* available. Christine Lubinski,executive director of the HIV Medicine Association, a Washington,DC-based trade group for AIDS docs, also urges HIVers to consider a county hospital or local government-run clinic. "When some private AIDS docs have closed, the best viable alternative is often the county health department or public hospital," she says. "These places will make room for you, and you shouldn't assume they're offering substandard care. Some of the best HIV specialists in the country practice in the public sector." The main drawbacks? Longer waits for appointments, crowded waiting rooms and more-outdated reading material.

Know Your HMOs From Your PPOs

There are basically three types of health insurance plans:health-maintenance organizations (HMOs), preferred-provider organizations (PPOs) and fee-for-service. HMOs offer you a network of doctors you will pretty much have to see if you want the insurance company to pay. PPOs also offer a network of doctors, but you have the option of going out-of-network, which, of course, means paying more money. PPO premiums are also higher than those for HMOs, and the fine print in your PPO plan may contain more restrictions on which services are covered.

But most experts say that in such states as New York and Florida,where HMOs are relatively new, it's best to go with a PPO if you can afford it. The less entrenched the HMO, the less connected it is to the local network of AIDS docs. More important, PPOs offer the widest range of physician options. "The hassle factor with HMOs can be enormous,"says Susan Dooha, director of health policy at New York City's Gay Men's Health Crisis. "You have to get approval every time you want to see a specialist." Dooha allows that many of her clients get frustrated with PPOs as well, especially when it comes to filling out paperwork or finding out which services are covered. But, with more choices, she says, HIVers often find a doctor or specialist they love who is not in-network. When you make that kind of match, Dooha says, it can lead to a profound improvement in the quality of your care.

Fee-for-service plans are the priciest, but they offer the most freedom in choosing a doctor. Basically, you can see whomever you want and you don't need prior approval for services. However, when these plans are affordable for the ordinary mortal, it is often because they cover a quite limited range of treatments. They also tend to have a higher deductible, which means that you might have to pony up the first$500 or $1,000 of your health insurance costs before the fee-for-service plan kicks in. Given the greed of the managed-care system nowadays, you're going to pay a hefty premium for the right to choose your own doctor and coordinate your own health care.

Reject That Rejection

Membership has its privileges, and belonging to a managed-care plan often entitles you to a generous ration of rejection: claims unprocessed and unpaid, services denied. The situation has become so extreme that two years ago the Connecticut attorney general filed suit against the state's four largest HMOs, charging them with denying patients care just to boost profits. Investigations by *The New York Times*and other media have found that insurers systematically

reject claims for services that they do in fact cover. The reason you may have to resubmit the same form numerous times and make repeated calls before you hear that the check is in the mail, many experts say, is that your HMO is looking to control cash flow.

Knowing the economic motives of your HMO will be cold comfort,however, when that reimbursement check keeps not arriving. But don't panic. Karen Kligler, a New York City-based consultant who helps patients battle rejected claims, prescribes persistence: Call the company, get the name of the rep "assisting" you and take detailed notes. While they'll sometimes acknowledge the mistake and correct it over the phone, they're more likely to point to some tiny technical error you, your doctor or their computer made -- and that will require you to start the process all over again. (Having the name and notes gives you a leg up if the claim is rejected a second time.) It may sound paranoid, but rejection is a policy pursued by the HMO on the calculation that you'll give up first. Don't. If you show them you're willing to fight, they may soon get the message, Kligler says. But if you still can't get satisfaction, Kligler suggests filing an appeal with the managed-care company.

Most states also have insurance departments that will adjudicate disputes with health insurance companies. In California, if your insurer turns down your appeal, you can file a complaint with the state's Department of Managed Care. The agency will try to render a decision within 30 days (click on www.hmohelp.ca.gov/gethelp, or call 1-888-HMO-2219). In New York, the state Department of Insurance allows you to file complaints online. Check out www.ins.state.ny.us/complhow.htm, or call 1-800-342-3736.

Kligler adds that you may want to take the time to write a letter to a local politician, asking them to do the same on your behalf to your insurer. Bad publicity is to managed-care companies what water was to the Wicked Witch of the West. Finally, you may want to consider hiring a consultant like Kligler to help. She takes no money up front but charges a percentage of whatever she manages to wrestle out of the witch. For a list of consultants who can help you beat your HMO, click on the website of Alliance of Claims Assistance Professionals, www.claims.org."The companies are betting that patients who get rejected are not going to fight," says Kligler. "But if you accept it, it's your loss. On the other hand, if you keep pounding away, in most cases they will reconsider and eventually pay."

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