Diagnosing In The Dark

A complex mix of symptoms and a shrinking number of aids physicians can add up to an OI (opportunistic infection) ID crapshoot. Your doc may dismiss diarrhea, fatigue or nausea as drug side effects even when caused by an OI or HIV itself. You can up your survival odds with info and attitude.

May 1, 2001 By Lark Lands, PhD

“I’m just lucky my own doctor was out of town the second time I went to the ER,” says Southern California PWA Ralph Davidson (not his real name). “Otherwise, I might be dead now.” Davidson’s luck took the form of an on-call experienced HIV specialist. The doctor, who spoke with *POZ* on condition of anonymity, immediately surmised that Davidson’s fever, night sweats and shortness of breath, plus a lab result showing anemia, could mean the fearsome MAC (*Mycobacterium avium* complex) and ordered follow-up labs. Even more important, he put Davidson on antibiotics right away. The doc knew that treating “presumptively” -- giving immediate care based on the most likely diagnosis -- is a must with this opportunistic infection (OI): In one study, almost one in four people died of MAC before getting their lab results.

The really scary part is that Davidson had come to the ER with identical symptoms three weeks earlier. That time his own doc just ordered a blood transfusion to counter the anemia and sent him home with a “That’s just life with HIV” nondiagnosis. No follow-up labs were ordered, and Davidson’s body was left to function as a petri dish for the explosive growth of deadly mycobacteria. Such botched diagnoses are one of the best-kept and most dangerous secrets of the HAART era, according to several AIDS physicians interviewed by *POZ*, who fingered three causes: 1) OIs, while declining, remain a threat; 2) rising side effects complicate the picture; and 3) fewer and fewer HIV docs have the perseverance or the experience to sort out the mishmash of symptoms.

But, hey, Davidson’s diagnosis was tough, right? After all, he didn’t have diarrhea, the most memorable MAC attack. Final answer: Diarrhea isn’t always an early MAC symptom, which means that Davidson showed up twice in the ER with a textbook picture of the OI, albeit one that his HMO doc had forgotten or never known.

Top HIV specialist Keith Henry, MD, says it’s time to sound the alarm. Citing a 1996 *New England Journal of Medicine* study showing that the more AIDS experience physicians had, the longer the survival of their PWA patients, Henry says that in 2001, treatment has only become trickier, while the likelihood of good care has decreased. He sees numerous trends converging to create “an ominous crisis regarding access to excellent HIV care” -- including a dearth of accurate diagnoses.

According to Henry, the problem springs in part from a mistaken belief that AIDS is over and that HAART has eliminated OIs. It isn't, and it hasn't. According to a recent analysis by the Centers for Disease Control and Prevention (CDC) of the medical records of 26,000 HIVers, the incidence of HAART-era OIs has dropped to 39 percent of the "old AIDS" incidence. But this trend is leveling off. Researchers at the University of California (at Berkeley and San Francisco) looked at causes of death in 56 Bay Area HIVers in 1998-99 and found that 45 percent had died of an "old AIDS" OI or cancer. Side effects of HAART or chemotherapy likely contributed to other causes, including liver or kidney failure (11 percent), cardiovascular disease (9 percent) and the body-wide bacterial infection called sepsis (12.5 percent).

Another problem, Henry says, is the complexity of what's happening in HIVers' bodies. First, HAART-takers may have difficult-to-diagnose symptoms from drug side effects. When meds lead to such maladies as diabetes or heart or liver disease, their symptoms create an even more confusing picture. On the other hand, worrisome woes such as diarrhea, fatigue or nausea may be dismissed by doctors as side effects when they are, in fact, caused by an OI, cancer or HIV itself.

To make matters worse, OIs can occasionally -- particularly when an HIVer with low CD4s first starts HAART -- appear unexpectedly as a result of "immune reconstitution syndrome." This paradoxical problem occurs when the antiretroviral meds have begun to improve the body's downtrodden immune function, but not yet enough to control infections. In this in-between stage, the immune cells wake up and start releasing inflammatory chemicals (cytokines) in response to latent infections (think MAC or CMV). The HIVer now has, thanks to starting HAART, enough immunity to produce the inflammatory reaction -- but not enough to fully control the actual infection. Result: Serious and dramatic symptoms may occur. "However," says William Powderly, MD, codirector of the Division of Infectious Diseases at the Washington University School of Medicine in St. Louis, "this syndrome is relatively uncommon and should not obscure the fact that OIs mostly still present with the same symptoms as they did five years ago."

Last, and happily, HIVers are getting older and, like any other post-spring chickens, are at risk for a host of age-related medical problems. So congratulations: That high blood pressure or those joint pains and muscle aches may have nothing to do with HIV disease or its meds -- you've just lived long enough to get creaky!

Worries that this mass of diagnostic knots emerges at a time when expert HIV care is harder to find. OI-savvy docs are burning out or retiring, while younger caregivers are OI novices, having entered the field during the HAART honeymoon. Meanwhile, budget pressures and the HMO-ization of health care discourage hospitals' aggressive diagnostic evaluations in favor of money-saving speedy discharge. Unfortunately, Henry says, "You don't get paid to look stuff up, read the literature, call a colleague or dig in deeply to solve the difficult puzzles. Being a physician who goes the extra mile for patients is a holy task, but when hospitals lose money due to government cutbacks, the patient-oriented extra time from nurses and docs gets eliminated."

For docs and patients desperately seeking diagnostic directions, longtime New York City AIDS clinician Joseph Sonnabend, MD, offers pointers. "In general, you don't look for multifactorial

causation in medicine, but HIV is the exception," Sonnabend says. "With HIV, always be alert for multiple diagnoses." He also urges aggressive diagnosis of the four most common -- and most ignored -- symptoms: anemia, weight loss, fever and diarrhea. Sonnabend says, "There is a tendency for docs who see a patient presenting with one of these four to just attribute it to HIV and choose to change, or begin, antiretroviral therapy rather than doing anything else. That's dangerous." If an underlying infection is missed, he says, "immune reconstitution syndrome might make the person dramatically worse when HAART is begun."

Sonnabend also urges docs not to get lazy by looking only for textbook cases of the most common OIs. Sure, one HIVer might show up with *Pneumocystis carinii* pneumonia's (PCP) trademark cough and CD4s below 200, but another may have CD4s so high and coughs so mild that PCP wouldn't register on most docs' radar: Washington, DC, HIV doc Larry Bruni, MD, recently treated two patients with PCP whose CD4s scored in the 700s. And when HIVers show up with either a rare OI (such as the brain disease PML, progressive multifocal leukoencephalopathy) or one that's rarely seen locally (maybe the fungal infection coccidioidomycosis, common only in the southwestern U.S.), even typical symptoms can go unheeded. Worst of all is a rare OI that shows up with uncommon features.

For a taste of the complexities of diagnosis in the year 2001, try these four common symptoms -- and the half-baked assumptions that docs may make about them:

Shortness of breath: Jane X. Austed drags herself into the ER short of breath, weak and fatigued. Is it PCP? Maybe -- but while Jane's lungs get checked, a full assessment with labs is a must. The same symptoms could result from anemia, which has a host of causes, including infections (such as MAC and tuberculosis), cancers (lymphoma and others), nutrient deficiencies (of B-12, folic acid and iron) and many drugs. Jane's symptoms could also result from other pneumonias, heart dysfunction or infection, Kaposi's sarcoma in the lungs, various fungal infections and asthma -- don't forget: HIVers get the same things everybody else gets, too. Of these, docs may be least likely to check for heart problems, even though HAART may cause cardiac disease. Before his death, Washington, DC's Don Poe spent several days in an infectious-disease ward being treated presumptively for PCP but growing ever worse. He told POZ, "I think they looked at way-gay me, saw my low CD4s, found out I was short of breath and leaped to a conclusion." The right cardiologist happened to be on hand when Poe's shortness of breath became severe, and he immediately identified congestive heart failure. With appropriate meds, Poe recovered, but later said, "They almost stereotyped me to death. Don't let them do it to you. Demand all the tests that anyone with your symptoms would get, not just the ones that fit their narrow framework for AIDS."

Diarrhea: Joe Runsalot shows up at his doc's office with a diary showing a half dozen bowel movements daily for months. Even his antidiarrheal meds don't help. Is it just his antiretrovirals? They certainly may be contributing, but UCLA's Peter Anton, MD, the world's expert on HIV-associated diarrhea, says that you should never presume that HAART meds are the only problem: Diarrhea often has multiple causes including infections or parasites (if CD4s have been below 100 within the last six months, MAC, cryptosporidiosis or microsporidiosis are most likely; with antibiotic use, suspect *C. difficile*), cancers (lymphoma, anal cancer or colon cancer), fat

malabsorption, lactose intolerance and functional bowel disease. Depending on your CD4s, your doc should use stool samples, biopsies and other tests to check for infections, including cryptosporidiosis, microsporidiosis, isosporiasis, CMV colitis, CMV gastritis and duodenitis, *C. difficile*, common ova and parasites, bacterial infections, MAC and candida overgrowth.

Fever: Kelly U. Arhot calls her HMO nurse to say she's been running a fever for weeks now, but her high CD4s make an OI unlikely and she has no other symptoms. Just HIV trouble? That's possible, but fever caused solely by HIV is uncommon in those who have CD4 counts above 300 and don't have malaise, fatigue, diarrhea or thrush. More likely is another infection, a cancer, a drug reaction or an auto-immune disorder. Although CD4s aren't a perfect guide, in most people with CD4s over 300 and no previous OI, fevers are usually caused by the infections or cancers to which even HIV neggies are susceptible, including: tuberculosis, bacterial pneumonia, herpes virus infections or sinus infections, food-borne infections, bacterial infections of wounds, incisions, catheters or IV lines, pelvic inflammatory disease, non-Hodgkin's lymphoma, Hodgkin's disease or endocarditis. In those with fewer than 300 CD4s, any of the above as well as almost any OI -- most commonly PCP, cryptococca meningitis, disseminated CMV and disseminated MAC -- may begin with fever as the only symptom.

Weight Loss: Mel Skinnyman weighs in with a 10 percent weight loss at his regular checkup. HIV causing wasting? Not so fast. Although HAART may help reverse weight loss if high viral load is making you burn up calories, it could also be a partial cause, as meds may contribute to fat loss. Consider these med effects, but also treat other possible causes: infections (might not yet have other symptoms), decreased calorie intake (due to mouth infections, dental problems, nausea, or loss of appetite), hormone deficiency (check testosterone), or cancer.

Look at the time frame. Research has shown that sudden, severe weight loss often precedes, and may even be an early warning sign of PCP, CMV, cryptococcal meningitis, tuberculosis and various bacterial infections. Slow, continuous weight loss often correlates with intestinal infections and diarrhea.

So with all this diagnostic drama, what's an HIVer to do? "The key to good care is having an experienced and HIV-knowledgeable physician who is motivated and has the time to do a good job," Henry says, "but they are on the endangered-species list. Pity the HIV patient for whom a good diagnosis and treatment could make all the difference -- and they don't get it." Shy of taking up residence at an AIDS-info motherlode like San Francisco General, there are no easy outs. But several docs are pushing for ways to systematically protect patients.

Renowned HIV expert Paul Volberding, MD, professor of medicine at UCSF, has long campaigned for reform in the education and certification of HIV physicians. He now celebrates the first step: formation of the HIV Medicine Association (HIVMA), set up through the Infectious Disease Society of America but open to physicians working in every area of HIV treatment, from family practice to pediatrics to oncology. Volberding hopes that the HIVMA will soon develop an exam to board-certify physicians as HIV-qualified. Docs would have to take recertifying exams every three years and accrue continuing medical education credits -- proof that a doc is keeping up to date.

Henry thinks an idea imported from Europe could also up the chances of improved HIV care: regional centers with experts in each area of medicine to consult with local doctors and ER physicians. Henry says, “In this way, they serve the public, the patients and other doctors, lifting up the whole level of care for an area.”

Such system-shaking changes take time. For now HIVers can increase their odds by searching out good docs and up-to-date info, keeping careful records and making appropriate demands (see “Save Your Own Life” below). No matter your symptoms, never give up, and never allow your physician to give up on you. Demand every lab test and procedure to narrow down the diagnostic possibilities. Use any means necessary -- wiles, wheedling, whining and worse -- until the cause of every symptom is clear, and every necessary treatment delivered. “We can all make misdiagnoses,” Henry says. “It takes a lot of work and a lot of tests, and even the experienced clinician needs to keep pushing. Just saying someone has AIDS is pointless and potentially disastrous for your patient. You just have to keep going until you solve the puzzle.”

SAVE YOUR OWN LIFE

Lost in the symptom swamp? Five simple steps to help guide you back down the path toward diagnostic safety.

Seek the best: If you don’t already have a highly knowledgeable HIV doc, get one. Word-of-mouth -- from other HIVers, AIDS organizations, or local hospital or clinic nurses -- works wonders. Greet all job applicants with “Are you a member of the HIVMA?”

Stay informed: Keeping up on the latest AIDS info -- through books, AIDS newsletters, conference summaries on the Internet and, yes, *POZ*-- can help you ask your doc informed questions and make appropriate requests for lab tests, diagnostic procedures and treatments.

Start a notebook: A symptom diary is key, describing exactly what you experience and when. Note every symptom, even if minor, from fever, headaches and diarrhea to blurred vision and memory problems. Immediately report anything that’s serious or lasts more than a day or two.

Keep records: Maintain a file with your up-to-the-minute case history; keep copies at home and with a friend. Include your symptom notebook, lab results in chronological order and a list of all of your prescription drugs, over-the-counter meds, herbs and vitamins. Bring it to each doctor’s visit or ER trip -- and pack it when you travel.

When your own doc is unavailable, this info will help the doc on call make the *right* call.

Insist, insist, insist: Don’t let your doctor ignore such common symptoms as diarrhea, anemia, fatigue or weight loss. If you hear the words, *That’s just HIV* or *It’s probably only your meds*, repeat after me: *“Run every test required to pin down the actual causes.”*Push your doc to look for multiple causes and, where appropriate,demand to be treated presumptively while lab results wend their way back to you.

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