Body Snatchers

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Women on protease ask: "Who is that in the mirror?"

"I'm the Elephant Man," Lesley Wasserman tells me. "I'm not a human. I'm an animal." After a few months on a saquinavir/AZT/3TC combo, the 46-year-old Santa Barbara, California, PWA's body began to blow up...and up...and up. Today the the self-conscious, five-foot-tall woman weighs in at 60 pounds above her normal 105. Her bust has swelled to size 42DD from a 38C, and she can't roll over in bed without first sitting up. Her back is in constant pain from hauling around so much weight. Every week she gains up to two pounds, even though some days she tries to eat as little as possible. "I'm not attractive anymore," Wasserman says. "I'm not interested in sex, and my body disgusts me." She pauses in an effort to reassure herself that despite her appearance, she's still the same person inside. "If it disgusts me," she continues, "it's definitely going to disgust someone else."

A year and a half into her protease regimen, Ann Birmingham (name changed) was undetectable, had few side effects and considered herself one lucky woman. Then the 28-year-old's body began its strange metamorphosis. "I was a stick with boobs," she says. Her waist barreled from 27 inches to 32. Her arms and legs shed their fat, leaving her with veiny, skinny limbs. Her butt became a muscleless sack of bone. The most striking change occurred in her breasts, a 36C bursting to a 38D. "When I walked down the street, you can be sure people weren't looking at my eyes," she says. "It was psychologically pretty horrific. I didn't want to leave my house. I didn't want to be seen by anyone."

Birmingham panicked. "At first I didn't attribute it to the drugs. All I knew was that my body was freaking out. If I had not been in contact with other women with HIV, I would have had no idea what was going on," she says. "I would have thought I was going crazy." After talking with her physician, she decided to stop her saquinavir/d4T/ 3TC cocktail. Within a month, her body normalized. She has, in a sense, deflated. While her breasts sag more than they used to and her waist is still a few inches wider, there's no doubt in her mind that the protease inhibitors caused these drastic changes.

Welcome to the new "AIDS look." Faster than you can say "triple-drug combination therapy," a slew of symptoms -- limb wasting, truncal obesity, breast enlargement or depletion, thinning of the skin, "buffalo humps" (accumulated fat across the shoulders), lipomas (fat deposits) -- is being added to Kaposi's sarcoma and corpse-like wasting in the HIVer's horror-house mirror. Although this fat-redistribution syndrome is an equal-opportunity menace, its effects tend to look more

dramatic on the female frame.

Expanding waistlines are one thing; disfigurement is another. Women with HIV, many of whom are already negotiating an emotional minefield of shame, guilt and sexual insecurity, are now faced with a new set of challenges. “These body changes are one more punishment that reinforces the feeling that ’Obviously, I’m not supposed to be in this body,’” says Karyl Draper, chair of the Los Angeles County HIV Commission. “Just when we were starting to tackle the psychological effects of HIV, these dramatic physical effects surfaced.” Add to that the lifelong pressure from society and the self to stay thin. The fat-is-bad view is so omnipresent, says PWA Mary Lucey, that when people saw women with wasting syndrome, the response used to be: “You look great, you lost some weight.” For Lucey, such comments prove how deep the “you can never be too thin” mentality is ingrained. The sad fact is, says Lucey, “She wasn’t not on a diet, she was dying.”

Although they don’t cause traditional HIV wasting, there is a growing conviction among PWAs that protease inhibitors are causing these new bizarre body changes. Many on the cocktails are having other problems, too, including unusually high blood levels of triglycerides, glucose and cholesterol. A handful of studies are underway, but so far no one knows how extensive these problems are, and the only evidence circulating in the scientific community is anecdotal. As doctors scratch their heads, PWA Donna Haggerty, 58, who says she looks and feels 12-months pregnant, avoids mirrors and admits: “If I won the lottery, the first thing I’d do is get liposuction.” More than a few PWAs already have.

Michael Giordano, MD, director of the AIDS clinical trials unit at Cornell University Medical College, says he first became aware of these body composition abnormalities when he and a colleague watched two female patients in hospital gowns walk down a hallway. Giordano commented that from the rear, the women looked like men. “I remember it very clearly. They had huge square waists and muscular legs.”

Giordano is one of several researchers around the country studying the causes and extent of this syndrome. Before last September, when a Washington, DCbased think tank, the Forum for Collaborative HIV Research, assembled doctors, patient advocates, and reps from drug companies and the National Institutes of Health, there had been no organized discussion or exchange of clinical evidence. Says the Forum’s executive director, David Barr, “Although this is an area of research that’s moving rapidly, as a patient myself I’m concerned about what we don’t know. The fact is, we don’t have a clue why this is going on.”

Word of these symptoms first spread last summer when a witty Crixivan user dubbed his or her fast and furious weight gain “Crix belly” on an Internet chat line. (Crixivan, [indinavir] manufactured by Merck Research Laboratories, is the most widely prescribed protease inhibitor.) Since then, warnings about “buffalo hump” and “protease paunch” have appeared with increasing frequency in AIDS publications (see “A New Kind of Waisting,” *POZ*, February 1998). According to Merck’s director of clinical research, Randi Leavitt, MD, the pharmaceutical is participating in several studies of this syndrome. “We want to gather as much information as we can in a systematic way,” Leavitt says. “We need to get a handle on what’s going on. We don’t understand

the mechanism that's triggering it." But while Crix belly may be the descriptor to name these body composition changes, fat redistribution is by no means unique to Crixivan. The other protease inhibitors appear to be causing similar side effects, and the condition has been recently tagged with a new medical moniker -- lipodystrophy, an abnormal distribution of fat.

February's Fifth Conference on Retroviruses and Opportunistic Infections saw the first formal presentation of syndrome data. While some doctors reported unusual fat accumulation in no or a low percentage of their patients, others described an incidence as high as 60 percent and noted the resulting potential for abandonment of otherwise-beneficial treatment. These symptoms did not surface in clinical trials, and some physicians and pharmaceutical reps suggest they may be an HIV-related syndrome unmasked by longer life. But activists beg to differ because there are many long-term survivors who hadn't exhibited such side effects until the advent of protease inhibitors. A stranger hypothesis: These metabolic changes may be triggered by improvement in PWAs' immune systems. But the bottom line, as John W. Mellors, MD, a leading researcher at the University of Pittsburgh, told a press conference at the Chicago confab, is, "We are in a period of ignorance about the prevalence of this problem."

Until recently, Barr points out, many less informed doctors did not know this syndrome existed or that it might be related to protease inhibitors, and explained the symptoms as being related to wasting syndrome. "I think a lot of doctors and patients don't know that these side effects are occurring and that they may be due to the drugs," Barr says. "For many people, this may just look like another symptom of AIDS." When it comes to weight, doctors tend to view any girth gained as a patient plus; they are even more grateful to see falling viral loads and rising CD4 counts: That combination is a bubble no one wants to burst. Mellors put it this way to reporters in Chicago: "I won't speak to more cosmetically sensitive areas, but in Pittsburgh there is no quiche or fluff, and if viral levels are down, it's good enough."

Good enough for an AIDS bigwig, but not for 47-year-old Nora Drake (name changed). When she went to her dermatologist to complain about veins on her legs that looked like glued-on ropes, the doctor said, "You have AIDS. You're wasting." She went to her gynecologist with worries about her disappearing breasts ("I went from a reasonable A-cup to looking like a couple of deflated balloons"). And then she went to an endocrinologist in near panic about the softball-size "gross blob of fat" growing on the back of her neck. "Nobody knew what was going on, and I was feeling grotesque," says Drake. "The hump was getting bigger and bigger to the point that I couldn't even bend my neck back. I never had anything remotely like this until I went on protease inhibitors."

When Drake went to the library and did some research. Gathering evidence from medical journals, she concluded -- as have some clinicians -- that Cushing's syndrome was the likely culprit. This condition, sparked by hyperactivity of the adrenal glands and high levels of the hormone cortisol, causes upper-body obesity, fat around the neck and thinning of the arms and legs. But when Drake reported her diagnosis to her doctor, his response was disappointing. Drake was missing the crucial factor that would link her condition to Cushing's, a treatable syndrome: Her cortisol levels were normal.

After bone scans, mammograms and countless tests to document every little fat composition variation, Drake couldn't stand it any longer. She had a biopsy of the tissue on her neck: It turned out to be a benign fat deposit called a lipoma. Last November, a plastic surgeon removed 60 percent of the hump -- a two-pound, yellow mass of tissue. Five months later, it still hasn't grown back; whether it will in the future has yet to be determined. Drake switched from Crixivan/d4T/3TC to Viracept/Fortovase/d4T/3TC, not only because her viral load shot up on Crixivan but also because the side effects were much too disconcerting. She has since gained weight in her thighs, her breasts are coming back a bit, and there's enough padding on her butt to now sit comfortably. But others with this strange syndrome who have switched or stopped protease therapy have less luck. Lesley Wasserman, for instance, went off her saquinavir cocktail and still continues to gain weight.

I am supposed to be a happy little camper because I'm on these drugs and I'm not dead," says Drake, referring to Mellors' "quiche and fluff" flippancy. "The attitude among some in the medical community is that you should just be happy you have the pills. I'm sorry, but I had a bony butt with a big stomach and a hump on my back, and that's supposed to be acceptable?" These bizarre physical changes are perceived as a purely aesthetic concern by some doctors, and the discrepancy underscores a basic dilemma for PWAs. As many try to stretch their psychic limbs to fit a suddenly expanding future, quality of life becomes a critical issue for women with body composition changes. Says Alexandra Levine, MD, a leading oncologist at the University of Southern California, "Each patient should determine with her doctor how important protease inhibitors are to her overall care vs. how debilitating the side effects are."

But gauging how troublesome these gradual transformations can be is difficult. That's why Dawn Averitt, founding director of Women's Information Services and Exchange (WISE), notes that body measurements should be a part of every physical checkup. She recommends that in addition to height and weight, PWAs should urge their physicians to measure their arms, thighs, stomach and chest. While fat redistribution has yet to push a significant number of women off the protease lifeboat, it may be a deterrent to those deciding whether to jump on. "This is one more thing against it," Averitt says. "We don't know if this syndrome is a result of toxicities, and we don't know if it's a danger to our health, and there's nobody right now who can tell us. Like everything else with HIV, it's a crapshoot."

The bigger unknown -- the elephant in the Elephant Man's room -- is whether this "cosmetically sensitive" syndrome is the tip of a health-disaster iceberg. Says Giordano: "We are telling people they have decades of life expectancy. If we're seeing this amount of endocrine dysfunction in only two years, are we going to see diabetes and heart disease or even osteoporosis down the line?"

For the moment, Ann Birmingham has chosen not to gamble on long-term protease-inhibitor use. Though she is acutely aware that this decision is not widely respected by medical professionals or, for that matter, by her friends and family -- going on and off and back on therapy can cause resistance -- she hasn't started taking the meds again. Birmingham says, "I need my body to find its way to being normal." As long as she was on the drugs, she says, others felt better that she felt better and was doing "everything" she could to help herself. Stopping treatment threatens this

complacency, and might strike some as willfully perverse, a twisted sense of priorities (fluff over health). But Birmingham points out that in the end, it’s a treatment option -- not a cure -- she’s refusing. Whether she’ll go back on a protease combo is hard to answer. “I don’t want to,” she says. “But the reality is, if my viral load shoots up and I get sick, I’ll have to. I’m feeling pretty good about being in my skin. I can now look in the mirror and recognize the person looking back at me.”
