Facing Facts: Dealing With Lipodystrophy

While newer antiretrovirals have reduced the prevalence of lipodystrophy, a significant proportion of the HIV population still suffers from the disfiguring loss or gain of fat in key areas of their bodies.

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The first time Nora Drake had her buffalo hump removed, the fat accumulation on the back of her neck weighed in at five and a half pounds.

“It was emotionally and physically debilitating,” recalls the 62 year-old Los Angeles resident, who prefers to use a pseudonym. “I was at the market one time and somebody that I knew came up and said, ‘Nora, is that you?’ She might as well have stabbed me in the heart.”

That was back in 1997. It was a time of great hope and rebirth for people living with HIV, but such optimism was counterbalanced by the harsh reality of the common side effects of the first generation of antiretrovirals (ARVs). Lipodystrophy—the loss or addition of fat in tissue—replaced AIDS wasting and Kaposi’s sarcoma lesions as the “face of HIV.” The look became instantly recognizable: fat loss in the cheeks, eye sockets, temples and the nasolabial folds running down from the nose and around the mouth, as well as in the limbs and buttocks.

“Being gaunt is one thing,” says Drake, who to this day has severe fat loss, or lipoatrophy, in her face and limbs. “But looking like you have wing flaps on your face is another.”

Lipohypertrophy, conversely, refers to fat gain, often in the breasts, back of the neck and shoulders, and abdomen.

Not only are these physical changes disfiguring and stigmatizing, instantly identifying someone as HIV positive, but they can also cause physical pain and are associated with cardiovascular health risks. Lipodystrophy often goes hand in hand with high cholesterol or insulin resistance, the latter of which can lead to diabetes.

Today, newer, less-toxic ARVs have greatly reduced the prevalence of lipodystrophy among people living with HIV. However, the legacy of the earlier years of ARVs lives on in the faces and bodies of those who survived those times, since the physical changes often endure well after major culprits

like ddI and d4T have been eliminated from most HIV regimens. (However, some still take AZT, which is widely implicated in lipodystrophy, mostly as a component of Combivir.) Furthermore, there is evidence that HIV itself, not just the drugs to treat it, can cause fat distribution abnormalities, as evidenced by studies conducted during the pre-ARV era.

David A. Wohl, MD, an associate professor of medicine at the University of North Carolina at Chapel Hill, says he believes that starting ARVs at a low CD4 count is a major contributing factor to lipodystrophy.

“I think we’re going to see less and less dysmorphic-type changes now that we’re starting therapy earlier, now that we’re starting therapy at higher CD4 counts,” he says. “I think a lot of what we saw was a remnant of letting people’s immune system’s go to pot and then rebuilding it, [along with] their metabolism, in a way that was not completely put back together the right way.”

Conjectures like these, unfortunately, are largely the name of the game when it comes to teasing apart the exact causes of lipodystrophy.

“I think the general understanding is we don’t have great understanding,” says Daniel S. Berger, MD, a clinical associate professor of medicine with the University of Illinois at Chicago and medical director of Northstar Healthcare in Chicago.

This is not to say that there aren’t answers for those seeking to restore their faces and bodies. And physicians who do such work stress that their efforts to help their patients in this arena go much further than skin deep.

“Psychologically, people get very depressed and people isolate themselves when they have these problems,” Berger says. “And by treating these issues, whether it’s fat accumulation or whether it’s loss of fat in the face, that generally improves people’s outlook on health and psychologically their sense of well-being. It does a lot for people.”

When attempting to gain insurance reimbursement for such procedures—which can be prohibitively expensive—Wohl says his office never categorizes them as cosmetic, but stresses that they are a reconstructive necessity and that the treatments will help improve physical function or mitigate pain.

In November 2010, the U.S. Food and Drug Administration (FDA) approved the daily injectable drug Egrifta (tesamorelin) to treat visceral fat accumulating around the liver, stomach and other abdominal organs. (Visceral fat is located within the body cavity, as opposed to subcutaneous fat, which is located just under the skin. Visceral fat cannot be removed by liposuction.) The drug operates by stimulating the release of the body’s own growth hormone, leading to the burning of abdominal visceral fat. Among those taking the drug in the two clinical trials that led to Egrifta’s approval, there was 12 to 20 percent reduction in visceral fat. But that figure is just an average, and for some, the results may be more profound.

“For the patients who do very well,” Berger says, “it’s a really nice product. However, unfortunately, when the product gets stopped, the fat accumulation returns.” He also notes that studies in HIV-negative adults show that a reduction in visceral fat can cut the risk of a major cardiovascular event. And because of the higher incidence of cardiovascular disease risk factors among HIV-positive individuals with lipodystrophy, and a greatly elevated risk of heart attack, he says it is believed that reducing visceral fat can thus reduce cardiovascular disease risk.

Published studies have shown that those taking Egrifta have seen improved levels of cholesterol, triglycerides and good cholesterol. However, there has not yet been research to show a direct connection between treatment with the drug and reduced risk of cardiovascular disease.

There are two non-permanent injectable facial fillers that are FDA approved to treat facial wasting in people with HIV: Radiesse and Sculptra, both of which stimulate natural collagen growth. Berger says he prefers to use Sculptra for larger areas and that he will often begin with a base of that filler and then, after two sessions, switch to Radiesse because the expanded access program for each product limits the number of uses. Otherwise, the price for each is steep: about $1,500 per office visit. Sculptra’s effects can last up to two years, cutting down on maintenance costs.

Another non-permanent injectable filler is Restylane, a hyaluronic acid that helps tissue maintain the water it loses as we age. Unlike with Radiesse and Sculptra, which take some time to produce results while the body produces collagen, the effects are immediate—“what you see is what you get,” Berger says.

An even more expensive procedure, but a more natural one, is an autologous fat transplant. A physician will harvest fat from one part of the body and inject it elsewhere. However, it is often difficult to draw fat from people who have suffered a great deal of subcutaneous fat loss across the body.

Collagen, which has a quarter century track record as a temporary cosmetic filler, has not been FDA approved for use in treating lipoatrophy, but it was one of the first fillers used to treat the condition. Zyderm and Zyblast are both bovine collagen, derived from calf skins, and require an allergy test, while CosmoDerm and CosmoPlast are human derived. The price tag is more affordable at about $600 a session; however, the product requires more frequent injections to maintain facial fullness.

Health care providers have largely soured on permanent facial fillers such as liquid silicone, which can drift, causing jowls, and which can also cause hard bumps called granulomas. Silicone cannot be removed.

Liposuction is an option for some people who experience visceral fat deposits. However, not only is it expensive, with insurance coverage very hard to come by, but as Nora Drake learned from having it done to her buffalo hump, the fat can often return.

Jane A. Petro, MD, president elect of the American Academy of Cosmetic Surgery, cautions people

seeking reconstructive work to find a practitioner who has a proven track record of being sensitive to the needs of people with HIV.

“Many physicians’ responses to HIV-positive individuals, despite legal and ethical guidelines, continue to be negative,” she says. “When seeking such health care, several approaches are possible. Who do the infectious disease physicians supervising therapy recommend? Some companies, like [Valeant Aesthetics, the maker of] Sculptra, provide free product for injection and would be aware of which physicians are using the product for this condition and are therefore HIV educated and friendly. Local community support groups may be able to identify HIV-friendly physicians as well.”

Outside of the physical manifestations of lipodystrophy, it’s important to monitor how the condition affects lipids, triglyceride and blood sugar levels. Medications may be required to help keep these levels in check in order to reduce the risk of heart disease and diabetes.

As for actually switching ARV regimens, studies haven’t shown consistent results proving doing so has much effect on lipodystrophy, unless an individual is taking the oldest of the ARVs implicated in the disorder, most of which have been put on the shelf of medical history by now. Some HIV therapies are more likely to affect lipids than others, though; and if those numbers are particularly abnormal and prove difficult to control, switching ARVs may be helpful.

Wohl stresses the important of a healthful diet and regular exercise.

“I don’t think people need to do anything radical,” he says.

Berger adds that, while there sometimes may be somewhat of a Catch-22 between reducing overall fat and exacerbating lipoatrophy, avoiding rapid changes in body weight, observing good nutrition and maintaining lean body mass can help protect against this effect.

On the flip side, he says, “I think we need to think about body image. We really are in a culture that lauds an idolized body shape that takes an incredible amount of work to maintain. In the media, what we see in our magazines, in our advertising is just incredible.”

Berger notes that the patients he sees who are able to better cope with lipodystrophy “may be older and more mature and recognize that as we age, we lose elasticity, collagen and other components of our tissue. So, more mature individuals tend to be able to get beyond this easier. And also individuals who are out about their HIV status and [have] a lot of their friends [who] are also HIV positive, and have nothing to hide about this—they’re able to get beyond this.”

Nora Drake, for one, relies on her wry sense of humor to cope with the changes in her body. After undergoing several difficult and painful attempts to get rid of her buffalo hump over the years, it still returned, although less severely as before. Her attitude about her appearance has also evolved.

“I’m figuring that since I’m a 62-year-old white female with white hair, I’m pretty cool,” she says. “I haven’t worn a bathing suit in a very long time. That’s a little scary. But I feel like finally I’m in an age group where everyone else is saying the same thing. So I don’t feel like I’m as singled out.”

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