The Bottom Line

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If you heard that in the past decade there was a 34-fold increase in any potentially deadly illness among PWAs, you'd be worried. But when the illness is anal cancer in gay male HIVers (as a recent Australian study showed), the good news is that you can take action that may preempt a future of painful surgery and chemotherapy. The problem comes when you seek medical advice about precisely how to do that.

"Talk about a pain in the butt! Just making decisions about anal cancer screening is that," says David Pauling (name changed) of Los Angeles. His anguish stems from the conflict between his doctors on screening methods. (For another PWA account, see "The Hole Truth.") In surprising contrast to doctors' unanimity about recommending periodic cervical Pap smears for women, the new call for anal Pap smears as early warning devices for anal cancer is far from universally accepted.

Strongly on the smear side is Joel Palefsky, MD, a leading anal cancer researcher and professor of medicine at the University of California at San Francisco. "I believe that anal Paps should be done on all gay men, whether HIV positive or negative," he says, citing the strong link between HPV and anal cancer, as well as his published data showing that most gay men have anal HPV infection. "No one knew that cervical cancer was preventable before Pap smears became widely used in the '60s and cut disease incidence by 80 percent. The hope is that a simple early-screening procedure for anal cancer would lead to a similar drop in disease and death."

Palefsky recommends that HIV positive gay men get screened annually as long as their Pap smears are normal, and HIV negative gay men every two to three years. He says there is insufficient data to make recommendations for HIV positive women or straight men. However, Stephen Goldstone, MD, a New York City surgeon who has treated anal lesions in hundreds of HIV positive men, says that women who have had cervical dysplasia (indicating HPV infection) and their partners should have anal Pap smears; even if they don't engage in anal sex, they may have transferred the virus via touch.

Taking simple periodic tests to detect cell changes that can offer early warning of a potentially deadly cancer seems pretty reasonable. So why the controversy?

"They're a waste of time," says Lester Gottesman, MD, director of the Division of Colorectal

Surgery at St. Luke's Roosevelt Hospital Center and an associate professor at Columbia University's College of Physicians and Surgeons, who has treated hundreds of patients. "They'll just confirm what we already know: Almost all HIV positive gay men are walking around with AIN" (bad cell changes that could turn cancerous; see "Anal Alphabet").

Gottesman is not against screening. He just recommends a different approach: a digital (finger) anal exam, combined with high-resolution anoscopy (viewing the anal area through a small tube with magnification, similar to the colposcopy for women), to look and feel for tissue hardening or irregularities. Suspicious areas can then be biopsied. "If you know what you're doing, you can feel or see changes before an area becomes cancerous," he says. Gottesman recommends repeat exams every three to six months as long as the findings are normal, and every two months if there are changes that warrant more frequent monitoring (but not yet treatment).

Although agreeing that this approach would be ideal, Palefsky says, "I don't see that happening in real life. The Pap isn't a perfect screening tool, but it is relatively convenient and far more likely to reach the at-risk population." He notes that in his recent study, 40 percent of HIV positive gay men had normal cell findings. Among those with suspicious cell changes, biopsies showed that only 5 percent had the confirmed high-grade cell abnormality (HSIL) results that warrant treatment. And he believes that even those who may not choose immediate treatment "are better off knowing their cell status and the resulting need for more frequent screening than if they weren't screened and diagnosed."

Regardless of the screening approach, all agree that treatment should be based only on biopsy results. And although they also concur that extensive surgery can result in severe pain and agonizingly slow healing, Goldstone says, "Not doing the screening means you don't find the small areas as they appear—when they can be treated simply, with little pain. That's how you end up with multiple large problem areas, and it's the treatment for those that can cause horrible pain." He believes that the sooner doctors start regular Pap screenings, the easier treatment will be in the long run.

Gay men, too, have to take this problem seriously, says Goldstone. "Many of our patients with advanced disease were too embarrassed or afraid to tell their doctors that something was going on down there. Or they didn't get screened because they weren't feeling anything." His conclusion: "Gay men need to know they're probably carrying HPV and need to get screened. This is not ostrich medicine where what you don't know can't hurt you."

Once you learn there is something there that could cause trouble—biopsy-proven HSILs—the doctors agree on treating with the absolute minimum of surgery required to remove abnormal cells, in order to create the least possible pain and recovery time. The problem area can be treated locally with trichloroacetic acid or liquid nitrogen (freezing it) if it's small enough, or via such outpatient procedures as laser ablation (surgery) or electrocautery (burning it) if it's larger.

Palefsky says that it may sometimes be appropriate not to treat HSIL and instead monitor frequently. This is particularly true if the area is large enough to cause a lot of post-surgical pain or scarring, which can lead to further pain and tearing with hard bowel movements or anal sex. After all, some estimate that less than 10 percent of HSILs will become cancerous. The experts agree that surgery is absolutely required if the doctor believes that invasive cancer might be present.

On the other hand, low-grade abnormal areas (LSILs) may stay that way, regress to normal tissue or progress. Palefsky will grant a patient's request to remove LSILs if the surgery is minor.

Pauling, the Los Angeles PWA, offers a blow-by-blow of his latest surgery: "First you get a Tylenol with codeine to relax you—you'll need it. Then you bend over, resting on your knees on a tilted table, with your butt in the air—a bit compromising. Then the doctor dilates the anus with the anoscope and coats the interior, to a depth of one to two inches, with acetic acid (vinegar) to see the lesions. A local anesthetic is injected to numb the area that will be destroyed. And, yes, the needle is a bit painful—but tolerable if you don't think about it too much. Then doctor inserts the electrocauterizer, a lovely device that burns the tissue, and begins removing the lesions. My most recent procedure lasted only 10 minutes, but some have taken longer. The post-operative pain and bleeding depends on how much tissue is removed. This time there was almost none of either, but when larger amounts of tissue were removed, I had both, although they ended after a few days."

Pauling knows other patients who have had much more extensive surgery, and then suffered terribly for months. He's a big fan of "less is more." Noting that researchers are developing HPV therapeutic vaccines and drugs such as imiquimod (Aldara), which may act indirectly to reduce HPV replication, he says, "By using the minimalist approach now, when those drugs are available, I'll still have my ass." But those therapies remain unproven, Goldstone cautions, and won't be available for years. "If you just wait for an iffy future treatment, your lesions may worsen and you may be left with no choice but 'hurts like hell' surgery." Makes regular anal cancer screening seem like an awfully good idea.

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