SENTENCED TO LIFE

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Part 2: Safer-Sex Survival

Safe sex, safer sex, HIV education, risk reduction—whatever the name, the guiding thread running through this effort for most of the past 15 years has been this: Put the fear of death into 'em.

The belief that they could very well face an unpleasant, lingering death did effectively motivate gay men, who turned condoms into a most necessary accessory. Of course, not everyone listened to the gospel of risk reduction—even in the days when infection was viewed as an inevitable death sentence. And by the early 1990s, studies were starting to show that an increasing number of men, especially young men, weren't being as conscientious as they once had been about safer sex. But there is no question that millions of people were saved—and that they were saved by those most basic of human emotions: fear and self-preservation.

But now, as hype and euphoria have started to spread about the promise of protease inhibitors as a treatment for HIV, many of those whose mission it is to spread the gospel of safer sex are growing increasingly uneasy. For if it does turn out that this therapy can change AIDS from a terminal illness into one that is chronic but treatable—and the jury is still very much out on that point—then death might no longer be the bogeyman that can drive the prevention message. And the fear is that there may be nothing powerful enough to take its place.

"Most people were willing to modify their behavior if the result of not doing so was that they were probably going to die," says Mark King, who is director of education at AID Atlanta. "The question is whether they will be as willing to change what they're doing if we tell them that the reason they need to modify their behavior now is to avoid taking expensive drugs five or 10 years from now."

This is a particularly troublesome question considering that even with the possibility of death as a motivator, some studies have shown that perhaps as many as half of all gay men weren't using condoms consistently.

"I don't think gay men want to use condoms. I think that's what it comes down to," says John Copeland, prevention programs manager for L.A. Shanti, an HIV care and prevention group in Los Angeles. "I think that pushing consistent condom use for the rest of their lives is a hard message to sell anyway. I don't know that this would make it any harder."

At this point, what little evidence there is about the decisions gay men are making about safer sex, based on the news about protease inhibitors, remains anecdotal and appears to be mixed.

At Gay Men's Health Crisis in New York City, David Barr, the director of treatment education, says that in the past few months, people have begun calling the information hot line to ask if they can toss away their rubbers. But he says those calls have represented a very small segment of the thousands of calls made to GMHC.

"There have probably been no more than 10," says Barr. "We're getting the questions, but we're not getting them that often."

Copeland, too, says people who work on safer-sex education programs at L.A. Shanti aren't seeing this issue raised that much in their direct contact with the public. But he says many of the doctors and health educators with whom the agency works are expressing worry that men might be discarding safer-sex practices.

For those concerned educators, the results of a small behavioral study among gay men in Florida, released in December, could hardly have been reassuring.

From the sun and sand of Miami Beach, from the shadows of all that art deco, from ground zero in the gay party universe, came this news: In a survey of 157 gay men, about half younger than 30 and half older than 30, researchers from Florida International University found that almost three-fourths had engaged in unprotected anal intercourse in the year before they were surveyed.

Before drawing too many conclusions from these results, it should be noted that Miami Beach is far from a typical setting. Its hard-charging party atmosphere is duplicated in few other places, and the city has long had the reputation of being a mecca for HIV-positive men, both of which could explain some of the lack of caution. But looking at possible reasons for the prevalence of unsafe sex, FIU researchers came to the conclusion that the news about the promise of protease inhibitors was likely a contributing factor, and they recommended that current prevention messages be rethought.

Clearly, experts and educators say, prevention remains the best option—even if protease inhibitors eventually do live up to their billing—for a variety of reasons:

• First, protease inhibitors aren't a magic "morning after" pill, readily available to fix the impulsive, poor judgment of the night before. People who view this therapy as akin to getting a shot of penicillin to cure gonorrhea are in for a rude awakening.

These drugs are administered through a demanding regimen that requires taking 20 or more pills each day, at specific times and under specific conditions. Some drugs have to be taken on an empty stomach, others after a meal. One of the protease inhibitors now on the market, Norvir, has to be kept refrigerated. Missing even one or two doses, or getting the times wrong, could render the whole treatment useless.

Patients will have to take all of those pills for at least a year—and possibly a whole lot longer. While some researchers at this point theorize that people might eventually be able to discontinue the drugs if the virus is eradicated, there is no long-term conclusive evidence to back up that theory. So the result of not using a condom could turn out to be enduring this pill-popping regimen indefinitely, perhaps even for the rest of one's life.

• Second, protease inhibitors are expensive—running from $10,000 to $25,000 a year, depending on what combination is used—and they can have severe and unpleasant side effects, including vomiting, nausea and diarrhea. Some patients have reported that their skin becomes so sensitive to pain that they can't stand for someone to touch them. Though not everyone develops these side effects, in some patients the symptoms become so severe and unpleasant that the treatment has to be discontinued.

• Third, while some studies have suggested that treatment with protease inhibitors can reduce the amount of virus in the blood to undetectable levels, there have been no studies establishing whether this renders people on protease inhibitors noninfectious.

Indeed, the possibility exists that having unprotected sex with someone who is taking a protease inhibitor could result in an HIV infection that, from the very first day, is resistant to treatment with the drugs. That's because any strands of HIV that remain in someone who is using inhibitors have likely survived by becoming resistant to them. For someone thus infected, the "magic bullets" would be blanks.

The transmission of protease-resistant strains of HIV is still a theory at this point. But the phenomenon has already been seen with AZT. Estimates are that as many as one in five people infected with HIV today will get little benefit from that drug because they were infected by people who were on the drug and whose HIV had developed resistance.

• Finally, and perhaps most importantly, it may turn out that protease inhibitors don't live up to their hype. These drugs were approved under an accelerated process by the U.S. Food and Drug Administration, without lengthy testing as to their efficacy. They have been used in clinical studies for about two years, and they have been in widespread use for less than one. So no one knows if they will be effective in the long term, or what the possible effects of long-term use might be.

If there is anybody out there who thinks that they no longer have to practice safer sex, they are wrong," says GMHC's Barr. "I would sit them down with a group of people who are on this treatment and have them ask what it is like. This isn't like a shot. It's not syphilis. It's not gonorrhea."

But even before protease inhibitors were added to the mix, many HIV educators already were rethinking the do-this-every-time-or-you'll-die approach, which seemed increasingly not to be working. At L.A. Shanti, for example, Copeland says prevention programming was recently changed to shift the emphasis from rigid insistence on universal safer sex to encouraging relationships inside of which wise, mutual decisions about sex can be made.

And Barr also says he believes safer-sex educators should perhaps not focus so much on a motivating message and instead try to tackle a more important underlying issue—why men make the decisions they make to have unsafe sex.

"Why did people ignore the message? It was not because they didn't understand the information," says Barr, who cites relationship pressures ('He won't love me if I won't...') and poor self-esteem as just two examples of why men sometimes make sexual decisions that are not in their self-interest.

"These are already very complex decisions for men. They are very difficult issues. We have to help them deal with these issues," Barr says. "I don't think anything is going to make that more complicated."

Part 3: To Work, or Not to Work

Though his health was starting to fail because of HIV, David Lanoux resisted mightily the idea that he go on disability. Self-employed in real estate, a series of illnesses had wreaked havoc on his income. But, having fought HIV with everything he had since 1986, he didn't want to give in.

Then, two years ago, he finally bit the bullet after a particularly nasty parasitic infection ushered in a dramatic decline where his T cells dropped below 100.

"Everybody said, 'You've got to do this,' " says Lanoux, 38. "So I did."

At his worst point medically, Lanoux's T-cell count had dropped all the way to two. He had embarked on a spiritual journey, and in his words, "I had come to terms with the concept of death."

Now, thanks to treatment with protease inhibitors, his T-cell count has risen to 87, his viral load is now undetectable, and he feels and looks much better. Indeed, he feels well enough to consider going back to work.

And therein lies David Lanoux's problem.

Because his income was so disrupted prior to going on disability, Lanoux qualified for the federal government's Supplemental Security Income program for the low-income disabled. He receives $484 a month in payments, but, more vital for him, he qualifies for Medicaid, which pays for his protease inhibitors.

If Lanoux goes back to work, his SSI payments will start to decline. That, he says, he could probably deal with. More problematic, though, is this: Medicaid is a program designed for the poor. With any kind of a normal income, he runs the risk of losing that coverage, which very well might mean that he would have to pay his drug and medical expenses—more than $1,500 a month—himself.

"Here I am, taking new drugs, feeling wonderful," Lanoux says. "I'm really very, very energetic and feel like I could be a contributing part of society again. But I'm held back by the cost of the drugs.

"I'm stuck in this pseudo-poverty situation."