KS Lesion

What kind of society pushes a confident man to cover his body with makeup and abandon sex?

February 1, 1995 By Scott Williams

“I was a very physical person, and I always got who I wanted,” says Gary Ebert, a 41-year-old San Franciscan. A 1984 photo from the Bay Area Reporter announcing him the winner of a local stud contest proves his point: He was one of the pretty boys, a swarthy, beefy, mustachioed hunk squeezed into a muscle shirt. Ten years later his skin, stretched over his broad frame, bears Kaposi’s sarcoma (KS) lesions on his face, neck, torso, arms and legs.

Gary developed his first KS lesion five years ago, but luckily it responded to treatment; the ragged, dark-purple stains were held at bay for the next four years. In 1993, after cryptosporidiosis and gastrointestinal CMV struck him simultaneously, his KS returned with a vengeance. He says the past year with KS has been the most emotionally draining. “I got really depressed and didn’t want to wake up. KS shut me down so much emotionally that I wasn’t able to perform sexually.”

Gary’s sentiments parallel those of hundreds of other gay men with KS. Although the condition is almost always less life-threatening than MAC or PCP, the social stigma that erupts from disfigurement may be more debilitating to the psyche. The gay community’s ruthlessly stringent beauty ideal is a formidable hurdle for men who must wear this scarlet letter of AIDS.

AIDS researchers have many theories about where and how AIDS-related KS develops, but no cause has been conclusively identified. Before the pandemic, KS was seen in elderly Mediterranean and Jewish men, sub-Saharan Africans and immunosuppressed organ-transplant recipients. AIDS-related KS appears most visibly in homosexual and bisexual men who live in or have sex with men in Los Angeles, San Francisco or New York City. And the use of poppers (amyl nitrates inhaled to heighten sexual pleasure) has long been associated with the likelihood of developing KS, although no study has yet proven this theory.

Speculation that KS is sexually transmitted has trafficked the AIDS treatment press and activist grapevine for years. Last December, a group of scientists at Columbia-Presbyterian Medical Center in New York City may have ended the 20-year search for a transmissible agent, isolating a new herpesvirus that may be a cofactor in the development of the disease. The herpesvirus was isolated in 93 percent of KS lesions from 27 men. (Two samples were negative for technical reasons: One was not KS and the DNA of the other was degraded.) “In gay men,” says Dr. Alvin Friedman-Kien, part of the research team, “we finally have reason to believe that KS is sexually

transmitted."

Physicians have historically treated KS as a cancer because it proliferates in a fashion characteristic of malignancies: In the case of KS, growth among a patch of tiny blood vessels, often near the surface of the skin, careens wildly out of control, creating a slightly raised, jagged-edges mottle no larger than a quarter. However, certain characteristics of cancers don't hold true for KS. Alternate scientific theories concerning the cause and origin of KS are now being actively explored. An expanding number of researchers now believe AIDS-related KS may be the final result of an interplay of many factors, such as the newly discovered herpesvirus, a suppressed immune system, wacked-out immune-system regulators called cytokines, possibly the tat protein of HIV itself, or a genetic predisposition to the disease (which prompts one to wonder, only half sarcastically: Could a KS gene be located near a gay gene?).

Some of the more compelling research on KS pathogenesis belongs to Dr. Barbara Ensoli of Dr. Robert Gallo's lab at the National Cancer Institute (NCI). Dr. Ensoli is currently exploring the role of the tat protein and basic fibroblast growth factor (bFGF) in KS disease development. Put simply, Dr. Ensoli's theory is that a cytokine called tumor necrosis factor (TNF), the tat protein and bFGF—a growth factor produced by replicating CD4 cells—interact synergistically to stimulate the runaway growth of KS blood vessels.

New York City's Community Research Initiative on AIDS (CRIA) is working with Dr. Ensoli's lab to gather samples of KS lesions from patients. Rick Loftus, who is coordinating the effort for CRIA, says, "We are looking to see if there are varying levels of bFGF (in the lesions). By looking at lesions of different sizes and at varying sites, hopefully Dr. Ensoli will be able to determine what role bFGF or other factors play in helping KS to proliferate in the overactivated immune system." If her theory proves correct, treatments tailored to thwart this biochemical process may follow quickly.

Unless lesions form in the lungs or on other internal organs, which is relatively uncommon, KS is not fatal. People with AIDS-related KS are more likely to die from other opportunistic conditions. So the primary goal of existing treatments is to ease pain and decrease the number or severity of lesions. Dr. Friedman-Kien—a New York City dermatologist who treated the first U.S. case of AIDS-related KS in 1981—warns that KS patients must be treated on an individual basis. "You must consider the disease stage of KS and HIV, any history of opportunistic infections and the toxicity profile of the therapy in question. There is no perfect therapy for all cases of KS."

That's an understatement. Treatments can be local (targeting an individual lesion or region of the body), or in cases of advanced disease, therapy can be systemic (treating internal organs or systems in the body). Researchers usually classify effectiveness of KS therapies into one or more of four categories: Complete response, or disappearance of all lesions; partial response, or 50 percent or more reduction in size or number of lesions; stabilized disease; or progressive disease.

Several therapies for KS are already approved. Cryotherapy, a technique in which lesions are frozen with liquid nitrogen, is one of the safest and most common local treatments. Eighty-five

percent of patients, including those with very low C4 counts, have complete or partial response, lasting from six weeks to six months. Mild scarring can be a problem. Blisters should be properly bandaged while healing, as blister fluid may contain HIV.

The cancer legacy of KS treatment carries on with the chemotherapy vinblastine (brand name Velban), which can be inject directly into skin or oral lesions. Physicians often have greater success with this treatment than with cryotherapy for lesions greater than one centimeter in diameter. Complete or partial success rates range from 60 percent to 88 percent. KS recurs in 40 percent of treater lesions within four to six months. Localized pain lasting one to two days and brown spots are vinblastine's most common side effects.

Radiation therapy can be beneficial for larger KS lesions or clusters of lesions called plaques. This treatment is usually employed for lesions on the penis, mouth, sole of the foot or around the eyes. It also may aid in the reduction of KS-relates swelling of the lymph nodes, legs and feet. Complete or partial responses to radiation are seen in almost 90 percent of patients; however, length of remission varies greatly, from six months to four years. People with skin irritation due to the radiation may try spreading fresh aloe vera over the treated area to alleviate discomfort.

Radiation treatment of oral lesions can be problematic. Painful tissue damage in the mouth may result in malnutrition and weight loss. Covering the oral lesions with the benzocaine anesthetic MGI-209 (Oratec Gel) prior to radiation treatment may prevent such pain.

A class of cytokines called interferons (IFNs) have been studied extensively as a systemic treatment for KS. Although physicians use several drugs for KS treatment, only two—IFN-alpha-2A (Roferon-A) and IFN-alpha-2B (Intron-A)—are specifically approved by the Food and Drug Administration (FDA) for KS. Therapy with IFNs is expensive and time-consuming. Patients treated with IFN-alpha may experience serious side effects such as neutropenia, anemia, fever, fatigue or weight loss. Greg Scott, a Washington, D.C. street activist and noted HIV sexual separatist, summed up IFN treatment with characteristic bluntness. "I hated it! I never felt this sick in my life. It was like a constant flu. Luckily, the side effects would subside somewhat after each treatment cycle."

IFN-alpha appears to be much more effective in people with higher CD4 counts. One small trial showed patients with CD4 counts of more than 400 had a substantial regression of KS lesions when treated with IFN-alpha. No patients with CD4 counts below 150 have shown complete or partial response rates in about 30 percent of patients, most of whom had CD4 counts above 200 and no AIDS diagnosis.

Despite the drawbacks of IFN-alpha, some researchers see promise in combining the drug with AZT or ddI. To counter neutropenia (a shortage of bacteria-fighting white blood cells), physicians sometimes prescribe a granulocyte-colony stimulating factor (G-CSF or GM-CSF). Combination of IFN-alpha and AZT has produced response rates of 40-50 percent overall, and as high as 30 percent in individuals with CD4 counts below 200. Likewise, Dr. Susan Krown, principal investigator of an IFN-alpha/ddI trial, has noted favorable responses with that regimen, too.

Advanced cases of internal KC require chemotherapeutic combinations, such as a cocktail of doxorubicin (Adriamycin), bleomycin and vincristine dubbed ABV. Other combo drugs include vinblastine and etoposide. ABV or BV therapy may produce complete or partial response rates of 80-90 percent. They are especially useful treatment options for people with KS in the lungs.

These combos are administered intravenously. Unfortunately, they may cause all of the very serious toxicities generally ascribed to chemo, especially in people also taking antiretroviral drugs. G-CSF or GM-CSF are prescribed regularly to alleviate neutropenia.

Several new KS drugs are in the pipeline. DOX/SL, formerly called Doxil, is a liposomal form of doxorubicin. The drug is encapsulated in fatty bubbles called liposomes that hone straight in on lesions; this also lessens many of the toxicities occuring with regular doxorubicin treatment. In a trial of DOX/SL, almost 80 percent of participants had a complete or partial response to therapy, one percent had disease progression, and only two percent had to discontinue therapy due to adverse side effects. If DOX/SL receives FDA approval as expected in February, it may become a logical substitute for the Adriamycin component of ABV.

DaunoXome is a liposomal form of doxorubicin similar to DOX/SL; however, DaunoXome does not directly target KS lesions as does DOX/SL. A phase I/II trial of DaunoXome showed complete or partial responses in about 70 percent of patients in the study. The most common side effects of DaunoXome are nausea and fatigue, each found in about 10 percent of patients.

Crazy proliferation of blood vessels is called angiogenesis: Inhibitors of angiogenesis are currently being tested against KS. TNP-470 has produced partial response in some patients, but the trial results are not final. SP-PG (Tecogalan) has been shown to decrease KS-associated swelling and possibly to reduce growth of lesions. Four U.S. trial sites are actively recruiting patients to test SP-PG. Activist Michael Marco, author of Treatment Action Group's widely circulated KS Report, is cautious. "It's really too early to tell with SP-PG," he says. "The drug reduces swelling, but we're not really seeing much else. The current dosage isn't really working, so researchers are going to try different doses."

According to Marco, one of the hottest drugs in the KS therapy pipeline is Taxol (Paclitaxel), a new drug that has shown substantial activity against cancers. "In the NCI trial underway, we've seen a 64 percent response rate among patients whose average CD4 count was 12," Marco says. Hair loss, fatigue and rash have been experienced by Taxol patients.

Another drug abuzz among KS treatment honchos is HCG (human chorionic gonadotropin), a hormone naturally released in pregnant women. Research from Dr. Gallo's lab suggests that HCG may hormonally inhibit the growth of KS lesions with far fewer side effects than more toxic therapies. POZ contributor Kiki Mason, who writes about living with KS in his Life column on page 66, reports some swelling—and morning sickness—on the drug.

Confused? The irony of so many treatment options is that none of them are clean successes. The TAG KS Report, published in mid-1994, was the first attempt to iron out the myriad issues around

KS treatment, the most prickly of which involve KS treaters, not treatments. Physicians are often reluctant to prescribe therapies, and two government research institutions—the National Cancer Institute (NCI) and National Institute of Allergy and Infectious Diseases (NIAID)—are too busy squabbling over the KS turf to focus on finding a cure. According to lead author Michael Marco, the KS Report was so well-received that NIAID Director Anthony Fauci personally called NCI Director Samuel Broder and Office of AIDS Research Director William Paul and told them to take TAG's Report seriously. "Broder has written me a total response on the recommendations in the Report," Marco says.

The only significant point of contention regarding the KS Report is over the issue of when to initiate chemotherapy. Dr. Joseph Sonnabend, an internationally respected HIV physician, is concerned that the Report "carries the views that treatment should be initiated as soon as KS is diagnosed. This is not an area in which there is general agreement," he says. "Chemotherapy is cytotoxic, and people with repressed bone marrow need to be cautious about treatments that can add to that, especially if there is a limited number of skin lesions that are not progressing rapidly and can be treated locally."

Marco is aware that he comes out being "pro-chemo" in the report. "I'm trying to dissuade the myth of chemo of your 70-year-old grandmother throwing up her guts and losing all her hair," he says, citing new drugs such as Zofran, an anti-emetic, that he says improves quality of life for people on the therapy.

Gary Ebert's chemo regime of alternating vincristine and vinblastine has helped contain his KS. "I've had some nausea and hair loss, but I think it's a good, basic treatment. It's really cut back on my facial lesions," he says.

Gary's life has changed considerably since the lesions spread over his body this year. His own discomfort with the blotches forced him to suspend his sexual and romantic involvements. Interestingly, he reports that a consequence of these grudging lifestyle changes was forward movement in other areas of his life, including finding inner peace and confidence.

"People inevitably notice the physical signs of AIDS and KS on my body," he says, "and that has really bothered me at times. On occasion, I've covered much of my body with makeup before going to the gym. But all in all, I'm a really secure person. KS has let me take a look at my inner self, something I kind of missed out on before I had the disease."

Gary Ebert has a point. KS raises questions beyond the clinical ones: What kind of society pushes a confident man to cover his body with makeup and abandon sex? What kind of cultural values compel the gay party circuit to send its fallen idols into self-exile? Why is it so unreasonable to say that this should not occur? Ultimately, KS is an ugly disease with ugly and painful treatments. What may be ugliest of all about KS, however, is the image of our community cringing in collective alarm over the sight of it. KS is mostly a disease of the surface, less deadly than pneumonia and easier to cure than lymphoma, yet it provokes an alienation of the men it afflicts more truly disturbing than either of these invisible illnesses.

In the end, which is really more sickening?

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