Out Out Damned Spot

The social stigma and health risks of KS are giving way to a treatment revolution

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Last year a horrific tale circulated after New York City's Black Party, one of the requisite stops on the national gay party circuit. A man with Kaposi's sarcoma lesions on his body had peeled off his shirt, like thousands of other men at the gala event, to join the swirl of sweaty, dancing hunks. A drunken queen accosted the man with KS and asked that he please put his shirt on. "You're ruining it for us all," he told him.

This incident epitomizes the kind of ostracism that causes dread in many gay men with KS. Since this blood-vessel cancer overwhelmingly affects gay and bisexual men, but rarely straight men, women or children, the condition has a unique social dynamic. With the gay community's stringent code of beauty -- a high hurdle for anyone, much less someone with KS -- the appearance of obvious lesions can send even the most balanced gay man into an emotional downward spiral.

Indeed, some men hide in a cave of isolation and fear after their lesions become apparent. This most visible manifestation of AIDS has even robbed some people of their livelihoods -- either by being fired or quitting due to embarrassment or harassment. These men must cope with a condition that disallows the choice of disclosure -- by advertising that they have AIDS.

Michael Callen, the late AIDS activist, author and singer, used to say that "90 and nine" was the diagnosis doctors often gave in the early '80s to people with KS -- meaning 90 percent would be dead in nine months. But now the prognosis for people diagnosed with Kaposi's sarcoma looks brighter every year, especially since the advent of protease inhibitors and more effective chemotherapies. Despite the numerous physical problems caused by KS, other opportunistic infections are often more life-threatening to people with AIDS.

Treating KS can be highly complex and -- like the new antiretroviral cocktails -- requires great care in assessing the individual patient's disease stage, prior therapies and potential drug interactions. "There's no cookbook way of approaching this," says Susan Krown, MD, attending physician at Memorial Sloan-Kettering Cancer Center in New York City.

Physicians experienced in treating people with KS know the disease's knockout punch: The social stigma. "I am aggressive in trying to get rid of every lesion," says Dr. Miguel Sanchez, who directs the dermatology department at New York City's Bellevue Hospital. "Although KS is often seen as a cosmetic problem, it is still devastating. The fear of disfigurement is a tremendous load to live

with."

David Varela, a gay Latino with KS who lives in San Francisco, enlisted an arsenal of treatments from colonics to chemotherapy in an effort to contain his KS.

The social stigma and health risks of KS are giving way to a treatment revolution lesions appeared from his face to his feet. "Things looked hopeless, so we were planning my funeral. I had a funny feeling that I wasn't going to be around for my 37th birthday," recalls Varela. But like many other PWAs, he was rescued with the latest anti-HIV drugs.

"Crixivan made the difference," says Varela, who stopped chemotherapy for his KS around the time he started Crixivan. "There's been some fading of my lesions. They're smaller and not as dark as before. They're still there, though. They're not completely gone."

Protease inhibitors have provided some relief for a large number of PWAs with KS. James Wernz, MD, associate professor of clinical medicine at New York University Medical School, says that the number of KS patients he currently treats has dropped by 75 percent in the past year alone. "I've found that their improvement correlates directly with drops in their viral loads. These were people who needed regular chemo before protease inhibitors," he says. Laboratory research has shown that protease inhibitors do not directly affect KSHV, the herpes virus that is strongly associated with the development of Kaposi's sarcoma (see "The Bug That Causes KS," [page not available]). Instead, the drugs appear to have an indirect effect on KS, reducing HIV viral load enough in many people to partially restore immune function. This, in turn, helps the body suppress the spread of KS and can result in regression of existing lesions.

Such has been the case with many of Wernz's patients, now off chemotherapy for six months but continuing to do well through use of protease inhibitors and other antiretroviral drugs such as interferon-alpha. "There's no question that antiretroviral therapy is now a mainstay in the treatment of Kaposi's sarcoma," Wernz says.

But Krown believes PWAs should not depend solely on protease inhibitors to treat their KS. Although she recommends a good antiretroviral regimen as the cornerstone for treatment of patients with stable health and limited KS, she notes that some patients have continued to show KS progression even with highly active antiretroviral therapy. Thus, she recommends careful monitoring and aggressive treatment of KS cases that fail to improve with antiretrovirals alone.

Most physicians interviewed agree with this advice. "You have to ensure KS is not spreading and there are no emerging lesions," says Dr. Erik Fleischman of Beer Medical Group in Los Angeles. "Otherwise you'll be chasing your tail."

Once Fleischman finds an effective antiretroviral regimen for his patients, he treats lesions according to where they are on the body in order to obtain the best possible results -- both therapeutically and cosmetically. "The art of treating KS is to use different modalities on lesions that appear on different parts of the body," he says. Some lesions can be frozen with liquid nitrogen (cryotherapy), subjected to radiation therapy or injected with the chemotherapeutic drug

vinblastine (Velban). “Overall, I get the best cosmetic results with radiation,” Fleischman says. “Velban injections are good for smaller lesions or facial lesions, but always go to someone experienced in KS treatment so that you get the best results.”

“My approach early in disease is often Velban injections and cryotherapy,” says Sanchez. “Velban causes hyperpigmentation, while cryotherapy bleaches the skin. I fine-tune these treatments for the patient to get the desired effect.”

While some people with KS have success with these treatments, they’re not without their side effects: Mild scarring (cryotherapy); mouth ulcers and other skin irritation, sometimes leading to weight loss (radiation); and localized pain at lesion site (Velban). And they must be carefully administered by highly knowledgeable practitioners.

Varela’s experience with both radiation and Velban injections left him marked with scars he bears to this day. “The injection therapy had awful scarring. It was worse than the KS in a way,” he says. “[My doctor] overdid it with the injections. Had it been smaller doses or fewer treatments, the scarring wouldn’t have been as bad.” Lesions the size of a dime became scars the size of a quarter.

To prevent such problems with radiation, leading cancer specialists recommend use of low doses, aiming for a level that will be effective without causing scars. Alexandra Levine, M.D., professor of medicine at the University of Southern California and a top KS expert generally recommends a total dose of around 1,000 -- 1,500 rads (given in doses of 150 rads per day for seven to ten days). Fleischman uses moderately higher doses of 1,800 -- 2,100 rads (given in doses of 300 rads per treatment, every other day for 12 to 14 days). He finds this dosage results in less frequent recurrence of lesions while preventing scarring.

Meanwhile, newer localized experimental therapies, such as topical retinoids and human chorionic gonadotropin (HCG), are bringing some success. Retinoids -- two common topical forms are known by the brand names Retin-A and Differin -- are vitamin A derivatives often used to treat acne and skin wrinkles. A few studies have shown daily applications of the ointment directly on lesions reduces their size. The best responses are seen on small, flat lesions. An added bonus is less toxicity than other treatments. Common side effects are skin irritations such as swelling, blistering and redness.

One topical retinoid currently being tested is Panretin, which seems to have greater activity against KS than some other forms of this treatment. In a trial of more than 100 patients, 30 percent had a complete or partial response. Panretin was tolerated well with minimal side effects. Trials of this drug currently are recruiting in about 35 sites, as is a trial of an oral formulation.

HCG, a hormone produced by the placenta in pregnancy, is the latest localized KS treatment showing promise. It is an approved treatment for infertility in women, low testosterone in men and failure of the testicles to descend in boys. In a small trial of 36 gay and bisexual men, investigators injected HCG directly into the lesion, and the hormone produced reductions or complete regressions in the treated lesions. Higher doses produced better results, and even some untreated

lesions showed some regression, suggesting systemic effect from the drug.

Side effects, not surprisingly, resemble pregnancy morning sickness. The treatment is very costly, and the specific dosage and preparation have yet to be determined. The drug is currently available for physicians to prescribe. However, in a press statement from Dr. Robert Gallo following the publication of the above study, he strongly advised that physicians thoroughly research the various preparations of this drug and method of injection for treating patients. The potency of different brands of HCG, and even of different lots of the same brand, varied greatly in this small trial.

The area where KS management has truly leapfrogged ahead in the past two years -- and saved many lives -- is the development of powerful new systemic, or bodywide, treatments. These are most often used for people with more serious KS: Lesions in the intestines that cause diarrhea or digestive problems, and lesions in the liver, spleen, lymph nodes or lungs. Lung lesions are the most life-threatening, causing breathing difficulties. (For those with less-serious KS, Krown sometimes recommends systemic therapies -- not necessarily chemotherapy -- to head off disease progression; alpha-interferon can add just the right “kick” to an antiretroviral regimen.)

Since 1995, new chemo drugs like DaunoXome and Doxil have replaced the old standby -- and highly toxic -- ABV (adriamycin, bleomycin and vincristine). Both DaunoXome and Doxil are encased in a special fatty coating to help lessen the often horrendous side effects, so they’re much easier for the body to tolerate than ABV. So far, results from these expensive drugs are very encouraging; KS doctors report that they have produced clear-cut life-extension.

“My patients have had great success using Doxil,” Fleischman says. “I think Doxil is far superior to DaunoXome, which I’ve found to be slightly rougher on the bone marrow and not as good at reducing lesions. As far as ABV goes, I see no reason to use it now unless patients are allergic to both Doxil and DaunoXome.” But Fleischman says he sometimes adds a low dose of vincristine (the “V” of ABV) to help prevent the development of resistance. However, some of his patients doing this have experienced transient peripheral neuropathy that subsides after two to three weeks. Sanchez also prefers Doxil over DaunoXome... “I don’t know many people who don’t prefer Doxil. I think it has an edge [over DaunoXome] in terms of its efficacy.”

But Wernz disagrees. “DaunoXome has gotten a bad rap. The recommended dosaging was inadequate. When I see patients, I routinely start them at 60 milligrams and use Neupogen if necessary [to counter toxicities]. I have no problem starting patients on DaunoXome first at this higher level of the drug.”

The FDA has approved DaunoXome as a “first-line” therapy and Doxil as a “second-line” therapy. Therefore, patients often start with DaunoXome and proceed to Doxil if DaunoXome is not helping. A trial of 227 patients with Kaposi’s sarcoma showed DaunoXome has a similar efficacy to the old standby ABV, but causes significantly less hair loss, neuropathy and bone-marrow suppression.

New data comparing Doxil to both ABV and BV suggest that Doxil is an appropriate first-line KS therapy, despite the FDA’s failure to approve it as such. Two trials that enrolled a total of almost

500 people showed Doxil produced a better response rate when compared to both ABV and BV, and had fewer and less severe side effects. Patients receiving Doxil had less nausea, vomiting and neuropathy. But some PWAs report that compared with DaunoXome, Doxil causes much more hair loss.

Steve Visscher is a New York City man with KS who's traveled a typical treatment path, starting with Velban injections, then BV, and on to Doxil and DaunoXome. "I was taking Doxil and started having itching and rashes, which my doctor thought might be an allergic reaction," he says. "So I switched to DaunoXome and haven't had any problems other than the usual [off-kilter] blood counts, for which I'm taking Neupogen. My lesions are now more or less stable, although one has grown a little." For his single lesion that's growing, Steve is considering radiation, which would be his first experience with that treatment.

Others have had similar success stories. "I got into a DaunoXome study in 1995, and shortly afterward my edema [swelling common in people with KS] dissipated greatly," says Steve Abbott, a San Francisco man who has had Kaposi's sarcoma since 1990. "I switched to Doxil last year because the DaunoXome nauseated me. Since I switched, my KS has been arrested and my quality of life has improved greatly." Abbott says he still has some nausea and swelling after his Doxil treatments, but Chinese herbs and acupuncture, respectively, have helped him counter those side effects. "I would absolutely recommend Doxil. Before I started treatment with these drugs, I was at the point where I couldn't even walk."

Clinical trials of another anti-cancer drug, Taxol, have shown great promise against KS. "As a third-line therapy, there's no question that Taxol is very effective in controlling advanced disease, especially among people who've been treated with DaunoXome and Doxil," Wernz says.

This drug is not specifically approved for treatment of KS, so patients have to receive it "off-label," which some health-insurance companies won't cover. And side effects can be severe, often including fatigue, bone-marrow suppression, itching, drastic hair loss, rash, fever and chills.

Like many other people with KS, when localized treatments failed to provide enough improvement, David Varela tried chemotherapy. But "the side effects like nausea and vomiting made me buy into that mindset of 'I really am a sick person,'" he says.

Indeed, drug side effects -- both those you see or feel and those showing up only on your lab report -- render chemotherapy unacceptable or useless for some people. Fortunately, other treatments can counteract some of the negative effects of anti-KS treatments.

Chemotherapy-associated nausea can be effectively headed off before treatment with the drugs Kytril and Zofran. There is controversy over the advisability of using corticosteroids, known to increase both KS lesion growth and risk of serious infection. And many PWAs report great success with smoked marijuana in the alleviation of their nausea. (For nausea home remedies, see *POZ*, March 1997.)

Another common -- and potentially very dangerous -- chemotherapeutic side effect is neutropenia,

or low neutrophil count, which can leave the body prone to a variety of infections. To combat this problem physicians often prescribe the drug Neupogen to stimulate the bone marrow to produce more blood cells.

Supporting the body with proper nutrition is important to avoid malabsorption of both food and drugs, a common problem with people who have KS lesions in the gut. “When people have visceral KS, it can greatly limit their intake of food, and nutritional absorption can be gravely altered,” explains Dr. Mary Romeyn, a San Francisco HIV specialist and author of the book Nutrition and HIV. “There may be a role for TPN in these instances. I encourage people to get tested for malabsorption and closely monitor their nutritional status.”

Proper supplementation with vitamins and antioxidants may help in other ways as well. Romeyn says: “We know that viruses proliferate in environments of oxidative stress, so I favor [antioxidant] supplementation for people with KS or HIV. Besides, it’s cheap and it won’t hurt you if used in proper doses.” Some nutritionists say antioxidants such as vitamin C and beta-carotene can also help counter the oxidative stress caused by radiation and chemotherapy, as shown in several studies in HIV negative people.

And anecdotal reports of high-dose (100,000 -- 300,000 IU daily) beta-carotene therapy have shown stabilization or even regression of lesions in some people with KS.

Like many other PWAs in 1996, David Varela found a lifeboat in the form of a protease inhibitor. His viral load went below the limits of detection, his CD4 count increased, and his lesions started to subside. Today, he radiates good health and an upbeat attitude about his future. But the KS that remains, he says, is an ever-present reminder of where this illness has taken him during the past three years -- and where it may yet lead.

“To gay men with KS, I would say: There’s much greater hope than there ever was before,” says this indomitable optimist. “Each year it gets better. Surround yourself with supportive people so you don’t have to deal with this alone.”

Indeed, overcoming the initial isolation is one of the most formidable obstacles to dealing with Kaposi’s sarcoma. The marginalization caused by this disease can be one of its most daunting challenges. After almost two decades of plague and all the horrors it has brought, now more than ever, acceptance and understanding should be the rules of the day.

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