

Telling Stories

Epidemic Beginnings

Douglas T. Dieterich, MD, FACP

He was uncharacteristically cheerful as he lay in the intensive care unit in Bellevue Hospital. It was December, 1980, and his name was Harvey. He had a mysterious illness with voluminous intractable diarrhea and a strange purple nose. We were called in to perform a small bowel biopsy on him to try and determine the cause of his diarrhea. It was a difficult procedure, but he was very cooperative. The biopsy was successful, but not revealing of the cause of his diarrhea or his purple nose. It was only after his autopsy several weeks later that we had some hints. The pathology report said he had Kaposi's sarcoma, an illness formerly confined to elderly Jewish men and Africans. The diagnosis was as much of a puzzle as the symptoms.

Twenty years ago this past June physicians throughout the United States were alerted to the first clinical symptoms of an elusive new disease that would forever transform the world landscape: AIDS. Harvey, as it turned out, was my first AIDS patient some 6 months before the report in *Morbidity and Mortality Weekly Report*, the Centers for Disease Control and Prevention publication that appeared in June, 1981. At Bellevue Hospital in New York, where the challenge of mysterious diseases was commonplace, we had just been through another new disease, Legionnaires disease, and had conquered it. At the time, with the optimism typical of young physicians, we thought the medical profession would determine the cause of *Pneumocystis carinii* pneumonia and Kaposi's sarcoma in these young men within about 6 months, as we had done with Legionnaires disease. We could not have been more wrong. Twenty years later, the medical profession is still battling the same virus, but the disease is completely different.

One by one, more young men appeared with Kaposi's sarcoma, cytomegalovirus, cryptosporidiosis, or other mysterious opportunistic infections with long names. As a gastroenterologist in those early days of the epidemic, I spent a large part of my time seeing HIV patients with severe diarrhea and with liver failure, typical gastroenterological diseases. By 1983 I was one of only a handful of physicians willing to see patients with this strange disease. Many physicians were afraid of this still-mysterious illness. One "expert" told me at the time, "I can't see those patients, I have a family and we don't know how it is transmitted." I am sure my thinking was colored by my personal experience of contracting hepatitis C virus from a needlestick

Douglas T. Dieterich, MD, FACP, is Chief of Gastroenterology and Hepatology at Cabrini Medical Center and Associate Professor of Medicine at New York University School of Medicine in New York City. He also serves on the International AIDS Society–USA Core Faculty, is Chair of the IAS–USA fall continuing medical education course in New York, and serves as a member of the Board of Directors of the HIV Medicine Association of the Infectious Diseases Society of America.

in 1977, while I was still a medical student. I, too, had been treated like a leper once when hospitalized for my hepatitis infection and I identified strongly with my AIDS patients' plight. I knew how it felt to be considered infectious. Most of us who were caring for these patients thought it was not just unethical for any physician to avoid patients out of fear of contagion, but dead wrong.

In those days, a patient would often be admitted to the hospital late at night, short of breath. *Pneumocystis carinii* pneumonia was the diagnosis. The patient's family—often in some place in the Midwest, like Kansas—would be notified. A day later they were in New York, faced not only with their son's mysterious illness but also with the fact that he was gay and that he was likely to be dead within weeks, if he survived the weekend. These were scenes of unimaginable heartbreak. Fortunately for the patients, surprisingly few parents turned away from their sick sons despite all their shock, grief, and fear at hearing the news. At the peak of the epidemic, many of us would lose 2 or 3 patients per week. This was a devastating situation, for which most of us, whom by circumstance became HIV "specialists," could never have been prepared. Most gastroenterologists and infectious diseases specialists were used to treating serious but treatable diseases. Suddenly we felt like we were in a war and losing. The best we could do was to provide comfort care for the dying.

The situation today in New York and other places in the United States is a far cry from those early days. Thanks to advances in antiretroviral therapy, instead of 2 or 3 patients dying each week, the number is maybe 2 or 3 each year. Instead of affecting mostly gay white men, the epidemic has moved to women and minorities. Interestingly enough, more than half of our HIV-infected patients are dying of liver failure caused by hepatitis C, the disease that drew me into the epidemic and made me more sensitive to my patients' illness. Hepatitis and liver disease are just two of many obstacles in the way of caring for those in the world fortunate enough to receive treatment for HIV. Side effects of the very medications that are extending the lives of our patients are the largest issue in HIV care today, not opportunistic infections as it was 20 years ago.

A vaccine remains one of our greatest hopes for conquering HIV/AIDS, but it is unlikely that a successful one will be developed for another 5 to 10 years. A successful vaccine will likely be one that produces cell-mediated immunity, not just antibodies as is standard in existing vaccines. So far, development of this type of vaccine eludes our grasp.

We can only hope that 20 years from now we can eradicate HIV from the body by using a combination of vaccines and pharmaceuticals. Until then, the hopeful message of our progress in battling AIDS is that physicians will get better and better at fighting the disease, one patient at a time.