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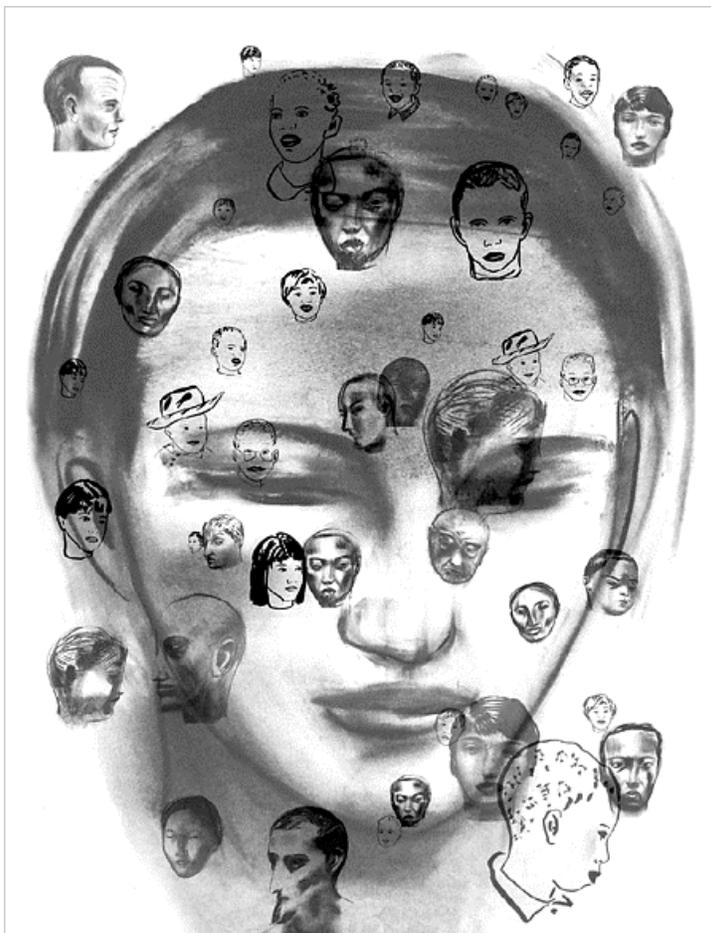
OP-ED CONTRIBUTOR

AIDS at 25: An Epidemic of Caring

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A quarter-century ago this week, when the Centers for Disease Control first reported the affliction we now know as AIDS, I was a 25-year-old medical resident. While I didn't even notice the report at the time, the milestones of my life and medical career — and of thousands of other doctors like me — have since been inextricably tied to the history of the virus.



By 1983, when I moved to Boston to begin specialty training in infectious diseases, I was well aware of AIDS. Like so many young doctors at that age and in that era, I was caught up in the "conceit of cure": the hubris that made us feel that science could find an answer to most things. On my first weekend on call at

Boston City Hospital I saw my first AIDS patient, a man about my age, and though I have since seen hundreds (perhaps thousands) of people with H.I.V., the image of his anxious face is indelible in my mind.

What followed over the next 10 years was a war, a long siege, with many casualties — every patient I saw would probably die from the disease that brought them to my office.

Like a combat veteran, I find myself compelled to describe to my current medical students (most of whom were not born in 1981) what it was like: how the metaphorical veil of shame and secrecy that traveled with this virus tainted everything; how being an AIDS doctor could distance you from other doctors, and even from friends.

When Robert Gallo and Luc Montagnier (or Luc Montagnier and Robert Gallo — a side story) discovered the human immunodeficiency virus, it felt initially like the siege had been broken. But in fact, the blood testing that followed simply revealed the enormousness of the global problem. While other specialties had their spectacular cures, their breakthroughs, it seemed as if those of us in infectious diseases had taken on the mantle of cancer doctors (except that oncologists uniformly had more cures and far better results than we did).

My generation of infectious disease physicians — most of us male and heterosexual — found ourselves transformed not just by disease but by the unique population of patients we encountered. We were more homo-ignorant than homophobic. The battle did not make us just empathetic; it left us with a deep regret that it took a disease like this for us to understand how much we could learn from gay men.

My patients taught me about courage, about bravery, about organizing for a cause, about dying for one. They left me with an abiding conviction that has not faded, the armor to shrug off the slings and arrows of pettiness and malice that we all encounter: there are bigger things at stake in life than just your happiness or mine.

We became zealots for the cause of our patients, even if zeal was all we had to give. We had no cure to offer, and so we began to leave the thresholds of our medical-industrial complexes and visit our patients in their homes, at their deathbeds. Paradoxically we discovered that our presence, our promise not to desert our patients, our continued care brought about a sort of healing, by which I mean helping the patients come to terms with their illness, with their deaths, and meanwhile diminishing for them the sense of spiritual violation that any serious disease brings, none more than this one.

I went at great personal cost to the international AIDS conferences; I watched with awe as politics eclipsed science and as gay activists rattled the cages of stodgy government entities like the Food and Drug Administration, and got results. I took my young sons to so many memorial services, for Jim, James and Jose — men who were my patients, but

who were also volunteers in our clinics, who were fellow soldiers in this battle and who were my dearest friends.

These men all died, and though they never lost hope, I did, as one drug after another failed to live up to its promise. I became a therapeutic nihilist. I did not think I would live to see the day when we had something that could really control the disease and extend life. When that moment came in America, with the drug cocktails in the mid-90's, I cried for all the patients I had known in four cities who would never have the Lazarus-like resurrections I could now bring about.

H.I.V. clinics changed. From being poignant settings full of brave laughter in the face of great tragedy, clinics were now all business, all about side effects and drug resistance. Don't get me wrong — I would not want to go back to the old days. But once treatment was available, the challenge seemed to be elsewhere.

Today I see so many of us who came of age at the same time now have one foot in Africa or Asia, as if we need the the kind of challenge we once faced here. It is as if we have carried the lessons of the AIDS protest group Act Up abroad, to prove that one can make a difference even in a poor country, one can find ways to pay for and distribute drugs, one can make an impact on transmission from mother to child.

I refuse to dwell on the numbers, the dire predictions and the pessimism about a vaccine, though I am sure there is some truth to all of that. On my desk I keep a picture sent to me by a friend, Rick Hodes, a doctor who has spent his professional years in Ethiopia. It shows a beautiful, chubby-cheeked Ethiopian child, wearing colorful local dress, and holding in his hand a photograph of a scrawny skeleton in rags. The photograph is of his former self, taken a few months before he got the H.I.V. medications that Rick scrounged money to buy. Victories are now to be won in that fashion, one child at a time.

I wonder now what I would have done if I had known in 1981 that AIDS would be as huge as it turned out to be. I am ashamed to admit that I might have gone into another field — say cardiology or gastroenterology. Which is why I have such optimism for the future, because I meet so many students and residents now who, knowing the magnitude of the problem, are still going into infectious diseases. They want to do something about global health, and have put their money where their mouth is by volunteering abroad before medical school.

I think perhaps that is the legacy of my patients, the legacy of the nurses and physicians' assistants and social workers who taught me so much, the legacy of people from all walks of life who toiled against AIDS when there was no hope. My students seem to know what we had to so painfully learn: the secret in the care of the patient is caring for the patient.

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