30 Years In, We Are Still Learning From AIDS

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At first it seemed an oddity: a scattering of reports in the spring and early summer of 1981 that young gay men in New York and California were ill with forms of pneumonia and cancer usually seen only in people with severely weakened immune systems.

In hindsight, of course, these announcements were the first official harbingers of AIDS — the catastrophic pandemic that would infect more than 60 million people (and counting) worldwide, killing at least half that number.

But at the time, we had little idea what we were dealing with — didn’t know that AIDS was a distinct disease, what caused it, how it could be contracted, or even what to call it.

As AIDS has become entrenched in the United States and elsewhere, a new generation has grown up with little if any knowledge of those dark early days. But they are worth recalling, as a cautionary tale about the effects of the bafflement and fear that can surround an unknown disease and as a reminder of the sweeping changes in medical practice that the epidemic has brought about.

Reports of the initial cases were confusing. The first federal announcement, 30 years ago this week, concerned “five young men, all active homosexuals,” with pneumocystis carinii pneumonia, or P.C.P., a disease “almost exclusively limited to severely immunosuppressed patients.” Initial suspicion fell on a known infectious agent, cytomegalovirus.

A month later, on July 3, 1981, I wrote The New York Times’s first article about AIDS, this one headlined “Rare Cancer Seen in 41 Homosexuals.” (“Gay” had yet to be accepted by The Times’s style manual.) The cancer was Kaposi’s sarcoma, and until then it had seldom been seen in otherwise healthy young men.

As it gradually became clear that the underlying illness was neither pneumonia nor cancer but a
sexually transmitted disease that was profoundly damaging the immune system, experts argued their many theories about the cause. A popular one held that the impact of combinations of microbes overwhelmed the immune system. Other theoretical causes included sperm deposited in the bowel, or some chemical that would damage the immune system.

It took three years to conclusively identify H.I.V., the virus that causes AIDS, and longer to settle disputed claims for the discovery. When doctors learned that it took about a decade to get sick from AIDS after H.I.V. first entered the body, they realized that people had been unwittingly transmitting the virus for years, spreading it to thousands of people in many countries, who in turn spread it to thousands and ultimately millions more.

Epidemiologists quickly showed that H.I.V. could be transmitted through heterosexual sex; from infected women to their newborns; in transfusions of blood and blood products; and via contaminated needles.

Patients and doctors feared the disease, often for different reasons.

Many doctors, uncertain whether AIDS was an infectious disease, refused to do essential procedures on their patients; sometimes superiors had to order them to. And while most doctors did treat their patients professionally and compassionately, they did fear they might catch the disease because no one knew how it was communicated. A few health care workers were infected when they accidentally stuck themselves with contaminated needles.

Compassionate care for the dying has always been a difficult issue for doctors of any age. But in the AIDS epidemic, many medical students and doctors in their 20s and 30s suddenly had to cope with dying patients their own age. Many senior medical school professors were ill prepared to advise them.

For doctors, nurses, patients and anyone who might be deemed at risk, the anxiety was pervasive. Might the first coughs or sneezes from a common cold or some other respiratory infection actually be a sign of P.C.P.? Might a small skin blemish represent Kaposi’s sarcoma?

Federal health officials and experts came up with a succession of names for the disease before they settled on acquired immune deficiency syndrome in 1982. (Some of the early efforts smacked of discrimination, like GRID, for gay-related immune deficiency.) But whatever it was called, it carried a bitter stigma.

Some patients were shunned by friends and relatives. Customers avoided restaurants for fear that
gay waiters would spread the virus. Some parents, fearing their children might catch AIDS from infected classmates, kept them out of school. Ryan White, a teenager with AIDS in Indiana, spoke up for all infected children and became a national hero before his death in 1990. His case also helped the medical profession address its obligation to care for all patients.

Communications to the public often lacked clarity. Because health officials and journalists used the phrase “bodily fluids” instead of specifying semen, blood and vaginal secretions, many people feared they could contract AIDS from toilet seats or drinking fountains.

AIDS appeared shortly after the eradication of smallpox, which had renewed declarations of the demise of infectious diseases. As a result, public health leaders were not well prepared to deal with a newly recognized deadly disease.

A common attitude was that all diseases were known, and all that remained for scientists was to fill in the blanks. For example, a newly recognized condition like Legionnaires’ disease was really a form of pneumonia. Yet it did not seem to occur to many scientists that novel agents might also be at work — even though viruses like Ebola, Lassa and Marburg, which cause hemorrhagic fever, had been discovered in just the past decade or so.

In covering the emerging AIDS epidemic along with developments like these, I tapped my training in infectious diseases and epidemiology. I joined my doctor friends in late-night telephone bull sessions to discuss the mysteries of AIDS. Some experts thought the agent must be a drug or chemical because no infectious agent fit. (The closest was hepatitis B, which became a model for research and precautions to protect people.) And some toxicologists used similar exclusionary reasoning to say no known drug or chemical could be responsible, so the cause must be an infectious agent.

Many published papers were flawed, despite leading medical journals’ sometimes arrogant insistence on a high standard of peer review. In December 1981, The New England Journal of Medicine published a long editorial exploring possible causes of AIDS. It never considered the possibility of a previously unknown microbe — a glaring omission and a leading example of scientists’ widespread failure to think outside the box.

Not long after, AIDS was finally linked to a relatively novel class of infectious agents called retroviruses. But the name, HTLV-3, placed it in the wrong category, and the incorrect classification caused confusion until the agent was correctly identified as H.I.V.

Discoveries of AIDS and H.I.V. were greatly aided by newly developed laboratory tests. One test
provided the crucial clue that the virus that caused AIDS was a retrovirus.

At the time, use of the CD4 blood count to detect serious abnormalities of the immune system was limited to a few research centers. Now, the CD4 and similar blood tests are standard in monitoring the treatment and severity of H.I.V.

Soon after the discovery of AIDS, scientists developed a molecular technique called P.C.R., for polymerase chain reaction, that can copy a single piece of DNA and multiply it countless times. P.C.R. has become a standard in monitoring an infected patient’s response to antiretroviral therapy.

In 1981, drugs against any virus were rare, and none were available for H.I.V. Now, more than 30 licensed drugs widely available in the developed world have turned AIDS from a death sentence to a chronic disease, though not necessarily an easy one to live with.

For several years, infected patients had to adjust their activities to the frequency and time of day they needed to take their medications. Now, only one multidrug pill each day may suffice for many. These antiretrovirals keep the infection in check, but do not cure it, and must be taken for a lifetime. New research shows that the drugs not only are therapeutic but also greatly reduce H.I.V. transmission.

For the patients who died in the early years, the wait for effective treatments — a decade or so after the first reports of the disease — was far too long. But that is a relatively short time in the history of medicine to develop treatments and preventions; after all, many incurable cancers and other diseases have been known for centuries.

The relative speed with which the therapies were developed owes much to the efforts of cadres of activists who demanded that the Food and Drug Administration loosen the rules for clinical trials and speed its drug approval process.

Efforts to develop anti-H.I.V. drugs have paid handsome dividends by leading to development of other drugs to treat other viral infections, like the liver diseases hepatitis B and C and certain types of herpes viruses.

Also, AIDS advocacy has spurred leaders of campaigns against breast cancer and other diseases to adopt similar strategies.

Soon after the discovery of AIDS, health officials mandated infection-control measures for health
care workers — wearing gloves and sometimes masks, gowns and other gear — to reduce risks from examining patients and handling blood and other specimens.

The AIDS epidemic also has put new emphasis on widespread public education, in schools and elsewhere, about sexually transmitted diseases. It has helped change medical practice by alerting doctors to the importance of asking about a patient’s sexual orientation and sexual history, matters not previously part of routine patient-doctor discussions.

The epidemic has brought a new focus on the power of epidemiology to identify a disease’s transmission patterns long before discovery of its cause. In the early days, epidemiologists provided the evidence to show that AIDS could be transmitted through contaminated blood transfusions, a fact many blood bank officials initially refused to accept. Later, lessons learned from AIDS were instrumental in helping control tuberculosis and curbing the spread of SARS.

Yet AIDS still presents extraordinary challenges — not least to journalists trying to chronicle the epidemic’s unfolding story, to remind a new generation of the importance of safe sex, and to follow the sometimes halting effort to make effective drugs available to all who need them.

One of the most daunting challenges is to stay vigilant until AIDS is at last conquered. Consider that it has been almost a quarter century since federal health officials confidently predicted that a vaccine would be available in the late 1980s — a promise that has yet to be fulfilled.