A Define Mess

Protease-era progress and pitfalls make “AIDS” Ã la 1993 obsolete. What’s in a name? Michael Scarce has the answer.

January 1, 2000 By Michael Scarce

In 1992, writer David Feinberg bemoaned the impending New Year’s Eve. Effective January 1, 1993, his official medical diagnosis would change overnight from “HIV positive” to “AIDS.” His health status would be no different, but the CDC’s definition of AIDS was: a CD4 count of less than 200 had been added as a qualification. In one fell swoop, thousands of HIVers-turned-PWAs nationwide rang in the new with a sense of what Feinberg called “psychological jetlag,” stuck with a life-changing label designed by politics as much as science.

Since the inception of the “gay cancer,” language has exerted an unprecedented influence on medical, social and psychological responses to the epidemic. Above all, as Feinberg, who died in 1994, lamented, an AIDS diagnosis is a powerful rite of passage (he considered throwing a party in honor of the occasion), transforming everything from income to self-image.

“AIDS” is arbitrary. A syndrome, it is nothing more than a laundry list of conditions and infections agreed upon by health officials. While the general public has a basic understanding of HIV transmission, even many AIDS professionals would be hard-pressed to recite the exact definition, and for good reason. The formula for what qualifies as a diagnosis is convoluted even by bureaucratic standards, and government agencies define it differently based on whether the goal is statistical surveillance or benefits eligibility.

Worldwide, “AIDS” varies enormously from country to country. Even though the World Health Organization has created a standardized definition, counting reported cases is so confounding an exercise that its AIDS program has given up trying and instead relies upon a software program called Epimodel for rough estimates. Industrialized countries that have the resources to monitor AIDS have seen fewer cases in recent years, while developing countries that lack surveillance methods face dramatic increases, further obscuring any meaningful snapshot of the epidemic.

The CDC’s objectives for the 1993 update were “to simplify the classification of HIV infection, to reflect current standards of medicine…and to categorize more accurately…mortality.” This revision was initiated by activists who pushed for a more inclusive definition as women (and others) were dying of HIV-related complications without ever meeting the official criteria for a diagnosis—and the attendant medical and social-service benefits. But seven years later, we find

“AIDS” poised for another overhaul, due mainly to the widespread use of viral-load testing, a better indicator of immune-system status than CD4 counts, and the effectiveness of HAART in restoring health and improving clinical numbers. Meanwhile, the multitude of HIV-related conditions has grown by leaps and bounds, as have the “current standards of medical care.” And not only has the number of AIDS-related deaths almost halved; the causes of death are new, too. As HIVers live longer on ever-changing drug combos, it becomes increasingly difficult to know if a particular illness or death is the result of HIV itself, the toxicity of meds (protease-related liver and heart problems, for example) or some independent factor (lifestyle, age or genetics).

Should we still draw a line between HIV and AIDS and, if so, where? The one-way transit from HIV infection to AIDS to death no longer accommodates the roller-coaster reality of rebounding health. Science continues to outpace public policy to an astonishing degree, and it remains to be seen how new technologies that measure drug resistance and pinpoint date of infection will reshape how both individuals and the epidemic are treated.

That the power to define is also the power to control is a lesson PWA self-empowerment learned well. As the current AIDS definition loses its relevance, it’s important to remember that the stakes keep rising for HIVers. In the process, fundamental protections that hinge on the diagnosis, ranging from disability status to government benefits to social identity, will be up for grabs. Beyond these upheavals, the collapse of “AIDS”—like the end of the “crisis” mentality that preceded it—also presents an opportunity to reimagine the epidemic—not only for us, in ways that safeguard equity, rights and assistance, but for the forces ranged against us. It may be time for HIVers and their advocates to put the AIDS redefinition back on their agenda—and the CDC on their travel itinerary.
