



Home testing: The metamorphosis of attitudes about HIV infection

Most of us have not spent the past 25 years on the front line continuously managing HIV-infected patients, but I am sure that at various points in our lives we all have been touched by the AIDS epidemic. Whether comforting a woman with knee pain in the office who is crying over the impending death of her son who lives in a group home for men with AIDS, diagnosing immune thrombocytopenia in a college student only to realize it is the seminal manifestation of his HIV infection, pleading unsuccessfully with several neurosurgeons to get one to perform a brain biopsy on an “enhancing ring lesion” in a young gay opera singer, or being part of a team caring for a gouty patient with AIDS and hepatitis C who had just undergone a successful liver transplantation, we all have our stories with resultant reflections on the era of medicine in which we practice.

In July 2012, the *New York Times* described the new home test for HIV infection as part of “the normalization of a disease once seen as a mark of shame.”¹ As with home pregnancy testing, people can now self-manage their need to know about what is going on in their body. But HIV goes so much deeper than this: it has been and remains a metaphor for and a reflection of many of the social issues that permeate our current political and social environment.

The politics and the social reactions to testing for HIV over the years since the virus was recognized in 1983–1984 is stuff for sociopsychologic treatises. Antibody testing was available in 1985, but in the absence of treatment, to test was simply to deliver a death sentence. Plus, with a diagnosis of AIDS, there would be no dental care, no insurance, no renting of an apartment, and perhaps no job. For some, family ties would be broken as closet doors would be thrown open, revealing a now unrecognized visage wearing the “mark of shame.” Some gay advocates rallied hard against testing, since anonymity and social protection for the infected could not be assured, a pragmatic response to blatant discrimination. In 1987, the first home test for HIV was in development, but—no surprise—there was no need for it.

As early treatments such as zidovudine (AZT) appeared and the value of specific antibiotic prophylaxis was demonstrated, there was some initial hope for treatment, and thus testing made medical sense. The size of the population infected (we were looking at the tip of the iceberg) was also being realized, so testing appealed to the social consciousness—try to limit infection. But discrimination wasn’t gone, and the politics of the time couldn’t quite handle all of the implications of a rapidly growing epidemic. America wasn’t ready for clean-needle-exchange programs, promotion of condom use, or open discussion of gay lifestyles. The Reagan White House was initially dead silent, except for proposing to limit entrance of potentially infected immigrants and promoting abstinence as the ideal protective approach.

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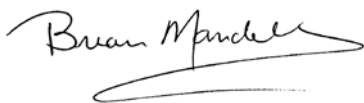
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Social righteousness took some hold, and protection of patient anonymity and autonomy became of paramount importance. But unintended consequences turned out to include limitation of testing: laws were written to require that HIV testing be accompanied by “appropriate,” stringently defined counseling, something that wasn’t always feasible. Patients needed to sign a release to be tested (“opt in”); many just said no. This tied the hands of physicians, so we developed work-arounds: we checked lymphocyte counts and CD4 counts to help us take care of patients too afraid to let us test for HIV directly.

Finally, in 2006, as therapies began to become increasingly effective and more data started to accumulate regarding the benefits of early antiretroviral therapy, the US Centers for Disease Control and Prevention recommended routine testing for all patients entering most acute health care facilities, unless they would actively decline (“opt out”). We have still not hit full stride in implementing universal testing for HIV. Nor have we hit our stride on fully accepting all demographic segments of the population. In some communities, HIV infection is still equivalent to the scarlet letter of Hester Prynne, not just because of the disease itself but because of the lifestyle it implies. Legislating laboratory testing practices cannot change all social attitudes. But maybe, hopefully, it is another step.

Dr. Christine Koval in this issue of the *Journal* (page 713) discusses the practical use of the newly approved home HIV test. It is a short article, but it took a very, very long time for social and political forces to be modestly aligned sufficiently for there to be anything to write about. Since perhaps 18% of HIV-infected Americans are unaware of their infection, maybe some TV ads for this test, wedged between the ads for treating erectile dysfunction, can indeed bring (as the *New York Times* described) further “normalization” to the approach to managing HIV-infected patients.



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REFERENCES

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