AIDS: Politics and Science¹

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There is an aphorism sometimes used by ethicists, to the effect that "Good data make good ethics." In the context of AIDS, it is interesting to propose, for purposes of policy analysis, that "Good data make good politics." The AIDS epidemic, which first surfaced in the United States in 1981 and is already massive in its global proportions, is putting social and political skills to their most extreme test; but it is a happy fact that in just 6 short years, biomedical and epidemiologic scientists have constructed a firm foundation of data on which to build policies that are carefully crafted to fit the precise contours of the epidemic. The yields from past investment in basic research, which once seemed extravagant to some, were mercifully available when the human immunodeficiency virus (HIV) first surfaced. The result is that, for the first time in history, humanity is in a position to respond to a major pandemic without panic and without resort to draconian extremes of social action (1). That is not what has been happening, of course, but it could happen if available knowledge were deployed wisely.

Sadly, much of the AIDS dialogue these days seems to be detached from reality, much less science. The general public evades acceptance of the extent of the tragedy and instead indulges itself in superficial complaints about the tastelessness of condom advertising. Even policy makers seem to be operating on the notion that the epidemic is a finite or short-term problem: that the "good old days" will return in 1991 or soon thereafter. When 5-year projections through 1991 were made at the Coolfont meeting of the U.S. Public Health Service in 1986 (2), anticipating 271,000 cumulative cases of AIDS in the United States by that time, the concreteness of those numbers seems to have given some people a false impression that the worst will then be over. The projections are, in fact, unusually firm, since the long incubation period—which may be as much as 8 or 10 years between onset of HIV infection and expression of disease—means that most of the individuals included in the 5-year prediction were in fact already infected and incubating their troubles. And yet, one hears people talk as if that projected 10-fold increase in AIDS cases will not necessarily happen or, if it does, that the epidemic will magically stop there and go no further.

One must dispense with such dreams quickly: AIDS is here to stay! It is like the day after Pearl Harbor in the United States—the world has changed and will never be the same again. AIDS will be a fact of life for our children's children; great efforts can be made to diminish the magnitude of the role it will play in their lives, but the virus cannot be made to disappear. The projections for 1991 might be low,

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but they will assuredly not be high; and nothing says there will not be a further stepwise increase in 1992 and beyond in the absence of public education and effective warnings—a national effort still not fully launched in the United States 1 year after the Coolfont meeting and 6 years after the start of the epidemic.

Finally, to finish off the matter of unrealism, while the options of quarantine, of universal mandatory testing, or of “not delivering health care” are often invoked as if they are real choices to be considered, they are in reality unthinkable. If one lesson stands out in 20th-century history, it is that there are “others”—that to declare one group of individuals to have lesser value or to be beyond help is to degrade all of humanity in intolerable ways.

Take quarantine for example: in the United States it is estimated that far more than 1 million individuals are infected, and knowledge of HIV supports the prediction that infectiousness will be lifelong (3). There is a tragic overrepresentation of minority and disadvantaged persons among that number (4), and there are also many of the most gifted and highly trained members of society: artists, musicians, writers, thinkers, and professional people—in fact, the flowering talent of a generation! They do *not* represent a threat to others except by the closest kind of consensual behavior; and yet in vague “opinion polls” the idea of quarantine sometimes has had the support of 25% of the U.S. population.

The logistics would be daunting to say the least: where would one find an appropriate island or enclave? How would they be fed? Would they make license plates for a living? One would certainly have to guard them to keep them from slipping out, and probably one would need to guard the guards, since the temptation to slip *in* would always be there for family members, loved ones, and individuals whose responsiveness to pathos or to sexual allure might overcome their caution. This all sounds so perverse that one hates to discuss it, but the winds of society leading in this irrational and dangerous direction are flowing strong, and silent contemplation of such atrocious options haunts the public policy debate in significant ways.

For instance, it seems likely that some thought of quarantine lies in the back of the minds of those policy makers who seem to be positively *possessed* by the remarkably tenacious wish to screen. When pressed to justify their position, advocates of mandatory, or widespread antibody testing to detect asymptomatic individuals fall back on the rationale that it would be desirable to know with greater accuracy how many people are infected. Since there has been little policy developed to deal with the number already at hand, that argument is peculiarly unconvincing. Furthermore, it is unnecessary to violate people’s privacy and autonomy to do that: one can get a very good idea of virus prevalence through anonymous samplings of collected sera.

A more serious argument in favor of antibody screening is that it should be deployed in order to interrupt further virus dissemination. But with that goal in mind a more profound issue arises concerning mandatory testing. Given that the very restricted modes of transmission are consensual and private in nature, limitation of virus spread is based of necessity on voluntary changes in behavior.

In fact, if mandatory approaches were effective in the social arena, there would not now be an epidemic of illicit drug use to serve as a major vehicle for further

spread of the virus of AIDS. Since intravenous drug use is already illegal, one could view the deployment of mandatory urine testing for drugs in the United States as an interesting "trial run." Thus far, the chief results of such programs seem to be, first, a black market in "negative urine" and, second (in reaction to that), a level of intrusive observation of the urine donation process to verify its authenticity that makes one shiver at the implication for AIDS control, but does not inspire confidence about the impact on drug use. Cost-effectiveness analyses of this approach to drug abuse are discouraging in the extreme.

Similarly, mandatory contact tracing in the context of AIDS is proposed by some with the argument that it is a "tried and true" method of control of sexually transmitted diseases, and premarital screening of blood for HIV antibodies is argued for on the same basis. Here too, the cost-effectiveness issue stands in strong opposition to such approaches, and in point of fact, the failure of standard policies to control sexually transmitted diseases has prompted extensive reevaluation and a majority of states have moved away from such unfocused approaches.

The history of efforts at the control of sexually transmitted diseases in the United States has been discussed in detail in Allan Brandt's book *No Magic Bullet* (5) and it appears that coercive social programs have not worked at all well. Even common sense would argue that *mandatory* contact tracing works only as well as the cooperativity of the index case will allow. And it can be cogently argued that efforts to enforce such heavy-handed public health approaches will simply ensure that the epidemic will go "underground" and that anonymous sexual encounters will continue (6). As to the inefficacy of premarital screening programs, *The New York Times* remarked dryly in an editorial recently, opposing such broad-brush responses to the AIDS epidemic, that the premarital syphilis test was dropped in New York State recently because "the results were not worth the cost, and because of suspicion that some couples nowadays have sex before marriage" (7).

Thus in two of the hottest of the current political debates concerning AIDS, the epidemiological data and scientific facts of the epidemic are not factored in at all. The very gravity of the epidemic situation should demand that critical assessment of past policies be especially keen, and if one is honest in such an assessment, it appears that penicillin, rather than public health officialdom, deserves the credit for curtailing syphilis. The explosive spread of antibiotic-resistant gonococci, and the advent of chlamydia and a host of untreatable sexually transmitted diseases among both homosexuals and heterosexuals that has been occurring since the early 1970s, stands as a warning not to be comfortable with past strategies. Even in the instance of smallpox—the only disease that has ever been eradicated—it is clear that administrative brilliance and focused efforts, based on a refined appreciation of the virus' properties and modes of spread, accomplished in a decade what a vaccine had failed to achieve in nearly two centuries (8).

Lest the discussion seem too firmly opposed to screening as a control strategy, the point should be made clearly that the horror of AIDS and its inexorable progress to an unpeaceful death is such that any political or ethical analysis would mandate whatever public health policies were best designed to abort the epidemic at the earliest opportunity. Much has been made about the intrinsic tension between civil liberties and public health interests, but the happy fact is that in the

context of the present epidemic and what we now know about HIV infection and modes of spread, the data lead to the conclusion that wise policies will optimize both civil liberties *and* public health.

That is not to minimize the usefulness of the screening test; indeed it can play a most important role in motivating individuals to amend risk-taking behavior and/or to protect their loved ones from risk. Its greatest use, of course, is in mandatory screening of the donors of blood and blood products and of organs/tissues/cells; such programs are clearly important and warrant the investment of extensive resources when possible, as has been done in the United States (9).

Antibody testing to detect HIV infection certainly plays an important adjunctive role in the context of counseling, confidentiality, and anonymity (if deemed necessary by the participant). There is much work to be done to improve this facet of its usefulness, however, for many communities have located their alternative test sites in the heart of the "inner city" or in the clearly labeled sexually transmitted diseases clinic, and the social disincentive to use services in such settings can be quite strong. The alternative of consulting one's physician has been advocated; but the medical profession is not yet well educated about the epidemic. Furthermore, bisexuality, covert homosexuality, and the patronization of prostitutes—not to mention the experimental use of illicit, intravenous drugs—are not common topics of discussion in the present-day patient-physician relationship. Policies that are designed to maximize use of the antibody test to identify infected individuals should be designed with these kinds of realistic considerations in mind, and testing opportunities should be designed so that worried individuals can learn their status and behave responsibly toward their loved ones, as most wish to do.

These comments are intended to demonstrate that the voluntary approach to control of the virus of AIDS has not yet been deployed as energetically as it must be. Data now support the fact that, in both the United States and Europe, when high-risk individuals have been educated to recognize the specific behaviors that put them at risk, the results in terms of behavior modification have been impressive (10–12). Compared with prior efforts of any sort at health education, much less sex-related health education, the magnitude of change has been dramatic. There is a particularly urgent need to convey warning information to individuals who have yet to adopt lifestyles: to adolescents and to children. To communicate effectively, one needs their willing attention, not their surly compliance, and the tone of preventive programs will do much to determine which attitude prevails.

As noted earlier, the central point about testing is that the antibody test is most useful as an *adjunct* to behavioral counseling, *not* the converse, and change in intimate sexual and drug-using behavior is far less likely to occur under mandate than it is by voluntary participation and cooperation. The human resources needed to conduct such counseling are in short supply. With blood screening and present testing needs, wasting such resources on poorly targeted mass programs is hardly wise. If further emphasis is necessary concerning the importance of counseling, it should be noted that the experience to date in the U.S. epidemic has suggested that the psychological impact of news that one is seropositive for HIV is extraordinarily powerful, that the maximum "suicide point" in the epidemic

thus far has been when people learn that they are infected, even more than when they learn of the diagnosis of AIDS.

This point is relevant in the context of so-called "routine" testing. In their eagerness to apply the antibody test more widely, some federal public health officials have advocated that the HIV antibody tests be incorporated into a diagnostic routine at the time of physical examination and "check-ups." This concept of a "routine" test may be flawed in its inception, however. Few people find tests such as electrocardiograms, serum cholesterol, or mammograms to be anxiety-free and ordinary when they pertain to themselves, and indeed the idea of routine testing is part of the unthinking and costly automatism in medicine in the U.S. that could well be improved upon. It seems far wiser to learn from the AIDS experience and personalize other tests, rather than to transplant bad habits into the proposed coping strategies for the future. (That raises an interesting point: there is no social problem presented by the AIDS epidemic that is generically new: the only really novel thing about AIDS, in fact, is the virus. All the difficulties are old ones left unsolved—and if the temptation to turn to the "quick fix" can be avoided and instead these problems are approached wisely, there will have been much societal progress if and when the epidemic comes under control.)

Because of the intensity of public debate, I have yielded to a tendency to focus on screening policies, but in fact much more important matters require attention. Public education campaigns probably occupy the position of greatest need, for the diffuse fear these should alleviate involves essentially all elements of society. It is a source of some perplexity to observers in other countries that the United States, with its vast numbers of infected individuals and tens of thousands of AIDS cases, has been extraordinarily slow to mount any educational campaign at all. The data are clear that there are only three routes of spread of HIV: sexual, percutaneous, and perinatal. That information should be accessible to all, so that persons at *no* risk can find themselves free to respond thoughtfully and react compassionately, and persons whose behavior puts them at risk will not be distracted by indiscriminate alarms.

Some of the hesitation to warn about specific risk behaviors has come from a kind of prudery, which is intolerable when the stakes are so high. The knowledge of modes of transmission that allows such a precise set of warnings derives from the rapid accumulation of scientific data over the past 6 years, but that remarkable scientific accomplishment could be neutralized completely by a narrow moralism that rejects mention of any option except monogamy or chastity. There is no society in human history in which those have been the sole patterns of sexual behavior, and the United States in the 1980s is surely not going to be the first! Failure to warn about the new virus and its lethal consequences is an extraordinary punishment for unapproved sexual activity, and there should be an ethical mandate to communicate what is known about prevention.

Condoms, for instance, are quite effective (although not foolproof) in preventing the spread of the virus of AIDS during intercourse when used appropriately (6); it is hard to believe, when condoms are among the perilously few defenses available to limit the spread of a killer, that someone could perceive silence as an ethically defensible stance. Worse even than the absence of public education is

the fact that some of the public laws mitigate against prudent behavior.

Then there is the matter of drug abuse: the issue of free needles seems to set morals aflame and it certainly distorts orderly discussion about how to block this major pathway of HIV spread. Again public laws seem wrong-minded, for most states in the United States have laws that make it illegal even to possess injection apparatus, and it is contended that easier access to needles and syringes would encourage drug use. In this regard it should be noted that some European countries have needle exchanges which have worked well and have not had that effect (13), but the issue clearly is not a simple one. Rather than rejecting such programs out of hand, the Institute of Medicine/National Academy of Sciences task force recommended that it be put to experimental test (3), for the fact is that drug use is the open avenue to the epidemic's future.

The needle argument is a distraction, of course, from the more profound problems with the U.S. "war on drugs." It takes the form of a "moral crusade," and yet no accommodations are made for prisoners of war: there are not now enough treatment slots in the United States to accommodate those addicts who already want treatment. During discussion of this issue in New York City during the Institute of Medicine study, it became evident that drug treatment facilities were so close to collapse from overload prior to the AIDS epidemic that effective messages about HIV risks might have the paradoxical effect of overwhelming them to the point of nonfunctionality. It is almost unthinkable, but true, that heroin addicts seeking help are told that they will be put on a 3- to 6-month waiting list. (It has been said sometimes that there is no evidence that efforts at AIDS education have had any effect on drug users: but it would be hard to discern an impact when there is no rational way for addicts to respond—addiction is, after all, a physiologic condition, not just a willful state of nonconformity.)

It is difficult to overemphasize the role that drug users will play in the AIDS epidemic, both in the United States and in many countries in Western Europe. By 1991 in the United States, the involvement of women will have increased from 7 to 9%, with either intravenous drug use or sexual partnership with a drug user as the major vehicle (3). More than 90% of pediatric AIDS in 1991 will be the direct or indirect result of drug use—and pediatric AIDS is a disaster beyond imagining, coupling as it does the sustained and desperate illness of immunodeficiency with the likelihood of orphan status, minority status, and neurologic decline (14). Even in the context of female prostitution, the likelihood of a prostitute being infected, and therefore potentially infectious, tracks dominantly with iv drug use (15).

Those, then, are some of the facts that should fuel public programs and should underlie political decisions. Some of the necessary words are difficult to say out loud in public, but they will have to become commonplace nonetheless. The fastidiousness that dictates against talking in plain language is predicted on the assumption that the situation is temporary, that the problem will go away. It will not, of course, and the thoughtful politician need not feel very brave in joining the debate now, for the future will validate the wisdom of frank and sensible approaches.

It is important to keep in mind that, in looking at *cases* of AIDS, one is looking at a snapshot which was taken 5, 8, or even 10 years ago—for the incubation

period is at least that long. While that picture from the past is useful many ways, the glimpses of the present—coming from the U.S. military screening programs, for instance—tell an alarming story. It is uncomfortable to note that volunteers for military service are infected at a rate of 2/1000 across the country; but it is horrifying to add that in the New York area where the virus has been available in abundance for a number of years, the rate of seropositivity among both men and women in the 18- to 25-year age group is approaching 2% (16). If we wait long enough before acting, the inefficiencies of heterosexual spread could be overcome in the United States and throughout the world, as they seem to have been from the start in Africa (17). Surely, there will be ways that clever political leaders can say that acceptably. It is an urgent need; there has been an almost ghostly silence from many responsible quarters thus far, and it is a source of great worry that in the future people will be shaking their fists and saying "Why didn't you tell us?!"

The present generation has spent much time worrying about thermonuclear bombs, and for good reason. But while those worries were ongoing, less than 30 years ago, a veritable microbiological bomb was quietly detonated in our midst. Now it is up to us to see whether we can mobilize what we have learned over the centuries. In an era in which silence and technology have been turned to with almost blind confidence, it will be a paradoxical challenge to face this new pandemic microbe without immediate recourse to drugs or vaccines, but that is what must be done.

Will we be able to modulate our public and private responses to fit the facts as we learn them; or will we overreact and try to build walls around our unfortunate fellow men and victimize them? Are we really any different from our distant relatives of the 14th or 18th centuries as they cowered before the Black Plague or the invisible menace of yellow fever? What can we learn from history and how do we cull the pertinent lessons from those that are archaic or irrelevant?

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