AIDS: challenges to our health care systems

JUNE E. OSBORN, MD

The presentation excerpted here was given at the Cleveland Clinic's Second Annual Update on the Acquired Immunodeficiency Syndrome in May 1989. At that time, the numbers herein were current. Since then, the number of reported cases of AIDS in the United States has surpassed 120,000, and includes more than 2,000 children; the number of American deaths from AIDS has exceeded those occurring as a result of the Vietnam war; and AZT has been recommended for use in both mildly asymptomatic and asymptomatic HIV-infected persons.

THE AIDS EPIDEMIC first surfaced in the summer of 1981. Clusters of cases involving rare infections or tumors on both coasts of the United States caught the attention of alert epidemiologists and physicians. Within a remarkably short time, heightened surveillance confirmed that a new disease syndrome was at hand, and that it reflected profound immunologic deficiency in previously healthy young adults. After a few false starts in nomenclature, the new complex of symptoms and illnesses was named the acquired immune deficiency syndrome (shortened to AIDS).

Within 2 years of those first case clusters, the virus responsible for the underlying immunologic defect was isolated and identified in the laboratory. Realization of the magnitude and scope of the human misery it would cause was much slower in coming, and no one could have anticipated the intensity of the social storms the disease would engender or its potential to short-circuit political will in the face of tragedy. The delay in development of comprehensive public policy has been nearly disastrous.

DELAYED AWARENESS

The astigmatic perception that AIDS threatened only peripheral members of society was distorted further by peculiarities of the American health care system to which we had become wearily accustomed. No one would have set out to create a system of health care and financing in which all the institutions and funding mechanisms focused on tertiary treatment and none on enhanced efforts of prevention or minimization of disability—and yet that is what we have. Nothing could be less helpful in the face of the AIDS epidemic.

Unfortunately for us all, the initial glimpses of the epidemic monster were misleading: intravenous drug users or gay men with a "fast-lane" life style and multiple sexual partners at first seemed to comprise the extent of its reach. Since these groups were "alien" to the so-called general public, the fact that something truly strange and deadly was happening to them caused only brief titillation. Even when the drug users' heterosexual partners—male and female—began to develop AIDS, conventional wisdom wrote them off by assuming that they, too, had been drug users and that heterosexual spread didn't really happen. In point of fact, most women who are sexual partners of intravenous drug users do not themselves use drugs; and yet they are becoming infected with alarming rapidity.

From the School of Public Health, University of Michigan, Ann Arbor. Dr. Osborn is Dean of the School of Public Health and chairwoman of the National AIDS Commission, appointed in August 1989 by Congress and the President. Reprints not available.

Unease increased somewhat when AIDS appeared in avowedly heterosexual Haitians, but potential insight was dismissed with tasteless jokes and innuendo about exotic rituals. AIDS began to appear in Western Europe, Australia, and Canada, and while most of those countries had the same epidemic pattern as that developing in the United States—dominated by gay men and intravenous drug users—some of the earliest European cases involved heterosexual men or women who had recently returned from Africa.

The inference that AIDS was not restricted to specific social groups was strengthened by the rapid emergence of heterosexual AIDS in central and east Africa. Curiously, the dramatic explosion of illness in sexually active young adults there, with a one-to-one male-to-female ratio, still did not raise American alarm. Some merely declared disbelief in the data concerning heterosexual spread; others ascribed transmission to dirty needles or simply assumed that the affected societies were so foreign that anything could happen. It was as if Americans thought of themselves as a different species, to which the experience of others was somehow irrelevant. Only when hemophiliacs and recipients of blood transfusions joined the accumulating tangle of individuals caught in the path of the burgeoning epidemic did it begin to penetrate public awareness that a genuine tragedy was upon us.

WHAT WE KNOW

Eight years have now passed since the first cases were recognized, and there is some good news and some terribly bad news. The good news is that we know with remarkable certainty how the new virus is spread and how it is not. This insight has permitted us to protect our blood supply and devise behavioral strategies for prevention of further spread. A policy of avoidance is a realistic personal strategy to escape the ravages of HIV.

The bad news is awful and getting worse. At first it was assumed that AIDS took 2 or, at most, 3 years to develop and that only a small percentage of those infected would become ill. Sadly, we have learned that the virus of AIDS often takes 10 years or longer to cause illness, so the epidemic may have been spreading silently for a decade before it was discovered. We still do not know how large a fraction of those infected with HIV will develop AIDS, but each year's additional experience deepens the gloom. Of a group of infected men studied prospectively after 9 years, AIDS has developed in half, fewer than 20% remain entirely well, and there is no sign of let-up.[1] Such data suggest that a very high percentage of HIV-infected people will ultimately become ill.

Discovery of the virus helped enormously in detecting silent infection. While HIV is slow to cause illness, antibodies to it appear quickly in blood, so serological tests could be devised to diagnose infection in people long before symptoms appeared. This provided a crucial tool to assist in protection of the blood supply, which had been seriously threatened both directly and by fear. As early as March 1983 the epidemiological data were strong enough to justify a policy asking that persons at high risk of infection through sexual and drug-using behaviors refrain from blood donation. As of May 1985 the universal screening of blood and blood products secured the blood supply of the United States and interrupted what could have been a much greater tragedy of blood-transmitted AIDS.

Viral isolation also facilitated efforts to find drugs to treat HIV infection and to devise vaccines to prevent it biologically. Despite the sophisticated science at hand, these goals have proven to be thorny and elusive. One drug thus far—AZT—has been found to extend the lives of those AIDS patients who can tolerate its toxic effects. It has played a limited but merciful role in ameliorating or at least delaying individual tragedy; but its toxicity and extraordinary cost put it well beyond the range of public health planning, and financing its equitable provision to persons with AIDS is stressing our national ability to cope, even at this relatively early stage of the epidemic.

As for vaccine development, all of the most apparent strategies of attack were pursued quickly and led to disappointment. This was perhaps not so surprising since most vaccines are devised by imitation of natural protective immunity; in the instance of HIV it is not clear that such a thing as a protective immune response even occurs.

CHANGING DISTRIBUTION

At first glance the distribution of AIDS cases seems to confirm early perceptions of the epidemic. The vast majority are still men, for instance, but if one looks closely, the most rapidly increasing group is women. There are still only a thousand pediatric cases, but it is estimated that those numbers will swell to at least 20,000—perhaps far more—in the next 5 years. Gay and bisexual men are still the largest category in both absolute and percentage terms, but intravenous drug users loom ever more important as AIDS patients, both in their numbers and in the difficulty attendant on their care. And the category of heterosexual AIDS requires close scrutiny: it still constitutes only 4% of the total, but in absolute terms that is more than the total number of cases reported by most countries.

Some other features of the statistics are chilling. Both Black and Hispanic minorities are over-represented by twofold or more, compared to their numbers in society as a whole. Already more than 70% of women and 80% of children are from those segments of the population. Their HIV-related illnesses are regularly superimposed on conditions of poverty and intravenous drug use. They live in an appalling swamp of disadvantage that threatens to mock our democratic ideals of equal opportunity and access to care.

It is important to remember that AIDS cases are out-of-date snapshots of the epidemic—the lethal denouement of infections that happened years ago. Current glimpses of HIV distribution suggest that more change is coming. In anonymous sero-surveys of hospitalized patients from parts of the country not centrally involved in the epidemic, the rate of infected persons was greater than 3 per 1,000.[2] Early data from college surveys have given similar results—2 per 1,000.[3] In screening volunteers for the US military, the rate nationally was somewhat lower—between 1 and 2 per 1,000; but in the New York City area, where the virus has probably had the longest time to "equilibrate," the military found a rate of infection tenfold higher (1.6 per hundred men and 1.3 per hundred women). As those numbers illustrate, the male-to-female ratio was approaching 1-to-1.[4] Finally, testing of all newborn infants' cord blood or screening samples has revealed rates of maternal infection as high as 1 in 77 live births in epidemic centers.[5]

EDUCATION WORKS

We have learned that our preventive knowledge can be used—that the virus can be stopped by education through frank and open discussion of risk behavior. In some of the highest-incidence areas of the population—the gay communities of San Francisco and New York—community-based educational programs have resulted in virtual cessation of virus spread. In those few areas where drug users have been offered help and guidance to diminish their risk of infection, what once was explosive spread of HIV has now leveled off.

The message is clear. We have a desperately important job to do to protect our children and our children's children. AIDS is here to stay. It is like the morning after Hiroshima. The world will never be the same. Our reticence about sexual and drug-using risk behaviors must give way to pragmatic strategies in the face of such a threat. Adolescence is an age of experimentation, but some of the experiments have turned deadly. There is an urgent need to communicate; and misinformation, including persistent stories about mosquitoes, intractable fear of casual contact, and denial of AIDS as "only a gay disease" will only serve to distract our kids from the important facts that can enable them to avoid infection.

THE HORROR OF PEDIATRIC AIDS

As heterosexual spread becomes increasingly important, there will be a steadily increasing representation of women among the HIV-infected, and as surely as night follows day, there will be children. This is certain to force a dramatic shift in the dynamics of health and social needs in epidemic areas where a preponderance of gay men masked the universality of the virus. The dominance of men among AIDS patients had been so striking in some areas of the US, where drug-related HIV transmission had not begun in earnest, that when the first wave of cases appeared involving women whose partners were bisexual, it had impact out of proportion to its numbers.

Single adult men are challenge enough; but when illness and death pervade a whole multigenerational family unit it is a far different matter! That is what is coming. In a household where the mother has AIDS, if there are two parents, often both are ill. Employment-related health insurance becomes a frail source of care as chronic disease manifestations emerge. Often there is only one parent (the index case) already so ill that she is no longer a caregiver, much less a provider. New York is the scene of some horrendous vignettes: older children, unaffected because their birth order preceded maternal infection, left standing like solitary trees in a burned-out forest after parents and younger siblings have sickened and died. There are not many of these yet, but there are enough to serve as a warning.

Of course all this means that there will be infected infants, and pediatric AIDS is a horror that defies imagination. By the end of the next 2 years AIDS in our country will begin to match, annually, the toll formerly exacted on children by congenital rubella. Some die fairly quickly, but some seem to share the tedious fate of older infected persons, and the equivocation of their future is brutal in itself.

Neurologic and systemic disease of children is not the only harm. Even when the children born to an HIV-infected mother escape infection, they may be doomed to stigma; for the *social* ramifications of participation in this epidemic, however indirect, have such force that an awful fraction of the 48,000 families in our country thus far suffering losses from AIDS have had to do even their grieving in secret! It may be difficult to reduce the toll of HIV on children, but at the very least we can and must protect those children from the ravages and pervasive costs of unwarranted fear!

WHAT ARE OUR PRIORITIES?

There is no question that the threat of discrimination, both actual and perceived, is the major impediment to effective public health efforts in the American AIDS epidemic, and it must be dealt with convincingly. Frightened people at risk cannot be coaxed forward to seek help and to learn how to protect their loved ones, and since voluntary, consensual behaviors are the conduit to future virus spread, we need their willing compliance in our public health efforts.

That need for measures to combat discrimination is not solely my opinion; it was at the top of the list of actions called for urgently by Admiral Watkins and President Reagan's hand-picked Commission on the HIV Epidemic.[6] Unhappily, it has not yet been activated as public policy.

The other urgent recommendation of the Presidential Commission was one with which I also concur wholeheartedly: We cannot consider ourselves to be fighting AIDS seriously as long as the drug epidemic is out of control, since that is the wide-open pathway to future virus spread. There must be drug treatment, on demand, for any addict who seeks it. Waiting lists of weeks or months make no sense when the interim is scarred by crime, debilitation, needle-sharing and a constant threat of HIV.

HIV ANTIBODY TESTING

While the technology of HIV antibody testing is excellent, it is still a biological test and thus has intrinsic potential for both false-positives and false-negatives. These can be dealt with by repetition and application of other tests, but these false results become important and potentially damaging to health care when the test is used as a rapid screening device that determines subsequent health-related options. In low-risk populations, far more false- than true-positives will register on a rapid screen.

I am strongly opposed to many mandatory uses of the test that have been the subject of innumerable legislative initiatives; but there are important constructive roles to be played by HIV antibody testing in the context of health care. The test is an invaluable clinical tool that can assist in optimizing diagnosis, treatment, and prevention. Firm information concerning HIV antibody (and infection) status is an important facet of overall assessment and counselling. It allows health care providers to guide the infected person concerning preservation of future health for as long as possible, and protection of loved ones or associates from exposure through sexual, drug-using, or procreative behavior. Such guidance can be individualized and optimized in the health care setting, and—importantly—provision can be made for reiteration and reinforcement.

The latter consideration is fundamental to the success of the enterprise. The news of HIV seropositivity can be overwhelming at first and can obliterate initial efforts at education for behavior modification. Indeed, the devastating impact of the news of a positive HIV test has proved to be one of the most potent stimuli to suicide yet devised—even moreso than the diagnosis of AIDS itself or of cancer; and that hazard is so reproducible that many experienced counsellors feel that delivering the bad news anywhere but in a health care setting is too dangerous to consider.

This constructive usefulness of the test in the context of individual health care is an area that will require real work. The concept proposed by the Reagan administration that testing be done "routinely" troubles me greatly for there is nothing routine about it, and its usefulness increases in direct proportion to the thought given to the clinical situation in which it is used. A negative test in an individual whose behavior is "high risk" can be seriously misinterpreted without guidance; and a positive test result may impose unbearable strain on an insecure patient-physician relationship.

HEALTH CARE DELIVERY

We cannot influence the fundamental fact that tens of thousands of young adults will need care in the next few years, and there is much to be done to enhance the quality and moderate the cost of that care; here is where it is important to emphasize the fact that there is nothing new about AIDS except the virus itself and the peculiarly awful constellation of diseases it initiates.

HIV infection causes chronic illness and, while there are intermittent emergencies that tax the resiliency of tertiary care hospitals, most of the needs of persons with HIV disease can be met in less sophisticated surroundings. We are in great need of institutions that would give us a continuum of care options: coordinated outpatient management, home care, long-term care and, for some, hospice accommodations could enhance the quality of life, extend the productive months or years of persons with AIDS, allow death with dignity, and at the same time diminish the strain on our existing health care institutions. That will require much work, for existing mechanisms of health care financing mitigate against such trends, favoring hospitals as the dominant vehicle for care.

What is needed in delivering a continuum of care to persons with AIDS will vary with each community. The option of a specialized unit worked very well at first in San Francisco, which set a standard for AIDS care in many respects; but numbers overwhelmed that model and it became evident after a while that the crucial components of their effective response were continuity of care and arrangements designed to optimize out-of-hospital life during the many months of intermittent debilitation prior to death. Case management was clearly a key element in the success of a multi-component approach to care, for someone needed to keep track of changing needs for home therapy, for support services that would conserve waning strength and facilitate longer duration of employment and the like.

With the advent of AZT therapy and such innovations as aerosolized pentamidine, the longevity of persons ill with HIV infection has been significantly increased, and with it all the needs for nonhospitalized care and maintenance have been intensified. AZT is not a trivial drug, for it is toxic to a degree that is tolerable only because of the disastrous nature of AIDS itself; so outpatient follow-up is critical to its usefulness. Efforts are underway to develop combined therapies, using AZT in combination with other drugs that have antiviral properties and different, nonsynergistic toxicities in the hopes that their combined impact on the virus can be optimized. But such strategies merely intensify the need for continuity of care in outpatient settings.

"WE MUST DO IT"

On a different note—we must do it. It sounds odd to have to say that, but there has been a tendency among the health professions to try to evade the AIDS epidemic. House officers have tried to avoid training in New York or San Francisco. Some physicians in non-coastal parts of the country have taken the stance that "it won't happen here"; but 80% of the rapidly accumulating new cases are being diagnosed away from the so-called epicenters and a new case is reported to CDC every 15 minutes.

Others have urged that AIDS specialists be trained and that AIDS care be localized to designated hospitals; but from what I just discussed it is evident that the best interest of patients and health care institutions and third-party payors alike is served by diminishing the role hospitals play—and with the numbers of patients sure to come, it is equally clear that AIDS and HIV infection will be part of the primary care agenda for years.

Finally—and most worrisomely—some have refused to care for patients with AIDS on the basis of fear of infection. The risk of contracting HIV in the health care workplace is less than one thirtieth the risk of contracting hepatitis B and far lower than the risk associated with half a dozen other pathogens! Even a bona fide needlestick straight out of an AIDS patient's vein carries a ask of transmission of less than 3 per 1000.[7].

That does not mean, of course, that there is no risk, but rather that the risk is at a low level compared to many other exposures that have been tolerated in the past. I support the policy of universal precautions, chiefly because it deals with the broad array of potential risks and recognizes the fact that no battery of diagnostic tests, however instant, can achieve complete protection. Adoption of the universal precautions approach recommended by CDC is an investment in safety that makes real sense, whereas efforts to force specific quick-screening requirements for HIV are likely to be ineffectual and, worse, to breed a false sense of confidence while seriously threatening the quality of care given to people who test positive, true or false.

PUBLIC POLICY NEEDS

Let me summarize public policy needs as they relate to health care for this epidemic. It is not irrelevant to note that we must do far more general education than has been undertaken thus far, for if the public were to grasp fully the very limited means of transmission to which HIV is constricted, it would go far to allay fear and, therefore, to facilitate compassion. We need school-based education to warn and arm our kids against this new reality. We need community-based education for target groups, including confidential testing and counselling, to facilitate cooperation on the part of those already infected and those at risk. They must learn—in language they can understand—how to protect themselves and others. The demands of the epidemic as it is currently projected will strain our means of coping to the limit, and prevention is crucial to the long-range outlook because there is a 10-year incubation period, and we cannot possibly tolerate continued escalation of the numbers of chronically ill young adults beyond those already projected far into the 1990s.

We need to restore calm to legislative processes so that precious resources are not squandered on low-yield, coercive screening initiatives that drive underground the people we most need to reach. In place of such mandatory broad-brush approaches, there should be much greater effort devoted to facilitating voluntary use of HIV testing, and we need firm antidiscrimination measures in place to allow people at high risk to come forward to receive education or care.

Finally we need to work hard at extending the range and flexibility of health care options, since that will yield benefits three times over: it will improve quality of care, it will moderate the cost of care, and it will pave the way to meet future needs of a steadily aging population for whom accommodation to chronic disease while optimizing quality of life will be a dominant concern.

And above all we must respond to this crisis with humanity and compassion. There is a quotation from Hubert Humphrey that I like to remember. He said "The moral test of government is how it treats those who are in the dawn of life—the children; those who are in the twilight of life—the aged; and those who are in the shadows of life—the sick, the needy, and the handicapped."[8]

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