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AIDS and the Social Order

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It had been 61 days – a long time in this series – since the last time I had spoken on AIDS before a public audience.

It was twenty-two days since I last spoke on AIDS before a public audience. Any reader who is not quite familiar of the day by day evolution of the understanding of the disease of AIDS and our response to it, might think some of the questions I raised in this lecture were far fetched or indeed out of place. Let me recite an anecdote, which may send some light on my concern at the time.

First of all, remember that AIDS was not talked about much in many countries of the world. Some of this was from embarrassment – embarrassment about having a disease in their country, but also the embarrassment of not having good statistics and the type of embarrassments about being afraid that the origin of the disease might somehow be pinned on them. (This was especially true of developing nations in Africa.)

Japan was very slow among industrialized nation to catch on to what people such as I were talking about and what American science particularly had come to learn. More than two years after this lecture, the understanding of people in Japan – including the health department, doctors and nurses, as well as the public really had an abysmal knowledge of AIDS. It was so clear to some forward looking people that as soon as I had left my post at the end of October 1989, a private businessman in Japan asked me to lecture on the history of AIDS and all of the social problems associated therewith in three cities in Japan. On the occasion when I spoke first – in Tokyo – the Health Minister was not only present, but also was my host at a dinner for approximately twelve people thereafter. As soon as we were seated at the table he raised his glass of sake and said: "AIDS, no problem in Japan".

No one could have accused me that late afternoon of being a diplomat. I practically shrieked across the table, "What do you mean, no problem in Japan? Let me tell you just one thing that troubles me greatly. Every day a number of jumbo jets fly from Japan to Honolulu. I know from out public health authorities there that these men frequently use

prostitutes. Their time in Honolulu varies from a few days to a few weeks. They return home to have sexual relations with their wives and AIDS is being spread heterosexually in Japan by these man who contracted the disease from prostitutes who have made their way to Hawaii!"

I needn't have worried about the diplomacy. I needn't have been embarrassed about being so vehement in my comments. I don't know what the other folks in the Department of Health thought when the Minister of Health again raised his glass of sake toward me and said: "AIDS, no problem in Japan".

That lack of understand and official denial may put the reader in a better receptive mood for understanding what follows here.

I didn't know before hand how many representatives of other Asian countries were present and because I know about the denial in Japan, I was extremely frank, but also I think – especially because of the language barrier – very articulate in what I said less there be any misunderstanding.

Remember that I was theoretically introducing my views of AIDS to a distinguished group of scientist. They might have been distinguished, but it wasn't because of their understanding of AIDS, and I assumed the ability to understand what I said, but realized that everything I said would be passed through the filter of denial.

I staked out my goal as "Some of the difficult choices that lie ahead of us relative to the pandemic of AIDS. By the choice of these words, I indicated that we had a global disease on our hands and that no matter what decisions might have been made publicly or privately, there still were choices ahead.

First, I reminded the audience that everything I said would be against the background that AIDS was:

1. It was still a mystery
2. That it was fatal
3. That people got AIDS by doing things that the majority of people didn't do and didn't like other people doing.

These three aspects of the disease in combination obscured many scientific issues and instead swung our attention to the more volatile issues of law, ethics, economic, morality, and social cohesion. The presents of AIDS was an affront to the moral standards of many societies and some of those had chosen to make the disease disappear by simply not publicly reporting its prevalence. It tried to hammer this home by saying that it was not a problem peculiar to the developing world. To save some face, I said that even in my country, which had been very candid about the prevalence of AIDS, we had to continue to provide encouragement and support to the total epidemiological effort in order to maintain our integrity of our health data without compromise.

Health data can, I said; contradict a nation's political, economic, social, or cultural life. Smallpox data once did that and malaria and tuberculosis still do.

I acknowledged that political and public health leaders in some countries did not want to collect and publish such data, and I urged them to relent, because without true understanding of a disease, we could not stop it. To make this clear I said that the last month the World Health Organization reported a total AIDS caseload in countries other than the United States to be 14,600. I even said that some countries had reported 1 case or no cases, while other countries sharing common borders sometime reported several hundred or a thousand or more. A totally impossible situation. I reported new figures from the United States a few minutes later as of just before I left home 43,000 number of cases.

I repeat again that some of these questions and statements may seem out of place to the casual reader, but they were very much a part of the evolution of our understanding of the disease and its unbelievable ramifications in our society. I went on to say that the disease of AIDS tests the very foundation of ethics in health care, and I cited the problems as being the denial of care by certain professional groups who refused to treat persons with AIDS, or even worse to treat persons whom they suspect could have AIDS, the avoidance of admission to hospitals whose beds were already occupied with AIDS patients, the avoidance of certain teaching hospitals for residency training because prospective trainees were willing to take less popular, less efficient hospitals rather than expose themselves to the possibility of transmission of AIDS.

This denial of services to people with AIDS is especially significant because AIDS is a protracted, extremely debilitating illness and one which is labor intensive. In other words, we need all the commitment of all the health professionals to get us through the next decade or so, as the disease progresses.

Although I had the feeling that my words were falling on deaf ears, I tried to make it clear that the disease of AIDS was not intrinsic to homosexuality nor to heterosexuality. I actually talked about homophobia as one of the results. (All during the AIDS epidemic, in the early years we kept using the term "homophobia", which did not express the problem. Homophobia refers to fear of homosexuals. Whereas, we needed a word that referred to the hatred of some cohorts of homosexuals. Obviously, my point was that health professionals must not in any way contribute to such irrational behavior.

The tradition in American goes back to the foundation of this country and Hippocratic tradition accepted by most countries, goes back for two millennia that we will not abandon the sick or disabled, whoever they are, or however the got their problem. I went so far as to say that I thought that kind of conduct threatened the very fabric of health care everywhere in the world.

That was a natural segue into a related issue which was a decision that had to be eventually made about what components about medical practice, if any, is dangerous to patients, if a physician, nurse, or whatever is HIV positive. A related question especially

relative to the neurological aspects of HIV infection has to do with who should be disqualified from performing certain jobs if they were HIV positive?

Then we got into economics. Especially what the costs might be and what special problems that presents for insurance companies. Our cost of caring of AIDS patients in the year of which I was speaking was, compared to later costs, was a paltry $1.6 billion, which at that time, $400 million came directly out of the tax payers pocket. We had to anticipate that the annual AIDS case load would double and the annual cost of care would more than triple.

That raised the next question. Would the American people continue to support high cost patient care for people with AIDS? I'd like to think the American taxpayer will do the right thing, but I don't know.

Then, of course, I shifted to what would countries less fortunate than the United States do with the same problems and I could not at that time of course, imagine what was being worked out before our very eyes at the time of preparing this information in emerging countries of Africa and Asia where everything I have mentioned heretofore is now an overwhelming burden to the point where some of these countries are essentially facing genocide of the age groups who make their countries run.

The next issue was individual privacy vs. the need to protect the community from danger. This issue was triggered by the availability in 1985 of the reliable blood tests to test for AIDS and to then decide on the confidentiality of the results of that blood test. This kind of decision-making was especially difficult in those societies just emerging from Colonialism and trying to follow their own pathways to a free and democratic future. Protective decision made by a fearful society to protect itself from supposedly dangerous people may, by itself, do more to define the nature of that society than any other effort or activity.

Finally, I turned to an American problem, which of course, would have its repercussions in other countries as well, and that was that the particular scourge that AIDS was for people who are young, Black, and Hispanic. One had to add poverty to all three of those and in countries where the population was totally Black, poverty had become one of the outstanding determinacy of the future of that country in reference to AIDS.

So we have to ask ourselves if we are truly mature enough to be color blind in the war against AIDS and I don't know what to say about being poverty conscience, because the response of nations in this year of 2003 to the overwhelming cost of AIDS in Sub-Sahara in Africa, up to now was not encouraging by a long shot.

Even though I didn't know the reaction of the Health Department of Japan two years after giving this lecture, I said with some trepidation and fear that it was falling on deaf ears that good sense and good science together could give the world something every bit as precious as the much desired AIDS vaccine, and would also show the world how compassion and justice could triumph over disease

The other subjects implied in the title were left for other speakers.

AIDS & economics
AIDS & ethics
AIDS & morality
AIDS & social cohesion
AIDS & the law
AIDS & the security of society
AIDS & young AIDS, & Black AIDS & Hispanics
AIDS as a mystery
AIDS as a protracted, debilitating, & terminal Illness
AIDS as a test of the ethical foundation of health care itself
AIDS as an affront to the moral standards of many societies
Caseloads & cost of AIDS in the future
Choices of the future in reference to AIDS
Cost of AIDS care in the United States
Defining the nature of society
Effect of AIDS patients in hospitals of future Admissions
Effect of AIDS patients in hospital on the attractiveness of training residencies
Effect of neurological AIDS on qualifications for some jobs
Embarrassment of countries in reference to AIDS & AIDS statistics
Health data, which can contradict a nation's political and social structure
Hidden scientific issues surrounding AIDS
Homophobia
Impediment to the practice of medicine caused by AIDS
Paucity of AIDS data from some countries
Privacy vs. the need to protect a community from Danger
Refusal of treatment in some AIDS patients
Role of compassion & justice in the management of AIDS
Statistics of AIDS currently in the United States
Statistics of global prevalence of AIDS and their Unreliability
Tradition of health care in America & globally
The need for total epidemiological effort
Violence against homosexual & bisexual men