

Blood, AIDS, and Bureaucracy: The Crisis and the Tragedy

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The politics of health were never tested more than when AIDS surfaced at the beginning of the 1980s in the industrialized nations. In those countries, it became the most important medical crisis of the last half of the 20th century. Today, the significance of AIDS remains as not only an unrelenting disease but also as a disease that continues to affect social and political life throughout the entire world. The connection between blood transfusion and AIDS is now under control in the industrialized countries but only because of lessons that took too long to learn over the past 25 years. That process had different roots

and effects depending on the various national blood programs and policies in different countries. That is illustrated by comparing events in France, Japan, Canada, and the United States that differed in donor and patient populations and on decisions made and secrets kept. Some of the problems persist to this day in parts of the world. Overall, the lessons learned from what happened with blood early in the AIDS epidemic apply to other aspects of human disease and could help in facing the new problems that are sure to appear in the future.

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WHEN THE AIDS crisis burst on the world scene in 1982, early mismanagement by governmental agencies of what was then a small part of total medical care resulted in enormously deleterious effects on the world's social policies, its economics, and its health. Those events offer a lesson in history that needs to be remembered to combat future potential disasters. Today, AIDS remains incurable still, and no vaccine has been developed; its effects can only be tempered. This report will deal with blood transfusion as the one aspect of early AIDS that became containable for different reasons in different countries. Even then that is still not true in parts of the world, and the other modes of spread of the disease are still rampant.

From earliest times, blood had been recognized as the messenger of the heart. The heart was always the home of the spirit, the soul, and the emotions and is still so celebrated today in song and story. When its messenger that had always brought life was identified as a messenger of death, public reaction to the medical usages of blood was irrational and uncontrollable. Where bureaucracies hesitated to recognize and meet the problem, the blood/AIDS relationship became a festering sore for 25 years.

THE BEGINNINGS

Unusual diseases were noted in the male homosexual community of American cities in 1981. Rare *Pneumocystis* infections were seen, as well as was Kaposi sarcoma in young men; unusual because that is ordinarily a disease of older age. There was an early relationship made to the practice

of anal intercourse, and the condition was given the name "gay bowel syndrome". As a cluster of signs and symptoms, it moved on to be recognized as the "gay-related immune disorder". At that stage of knowledge, diagnoses were made in the dying and the dead, and occurrence was considered universally fatal.

There were many theories for the cause and spread of the new affliction. Because of its preponderance in male homosexuals, interactive events in their social exchanges were described to a shocked public. It read about San Francisco's bathhouses and the irregular sexual practices there and the use of amyl nitrite to heighten responses. A fear of any contact between people spread. Police officers wore masks just as they did with the 1918 flu epidemic. To this day, health care workers wear gloves before touching patients and dental workers add total face protection; steps not to protect the patient, but to protect the worker.

By September 1982, the Centers for Disease Control and Prevention (CDC) was calling the syndrome "acquired immune deficiency syndrome" (AIDS) in its *Morbidity and Mortality Weekly* and had defined its parameters. It described almost 600 cases and divided them into groups as 75% homosexual or bisexual males, 13% intravenous

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drug abusers, 6% Haitians, and 5% other including 2 with hemophilia A.¹

Body Fluids: Semen and Blood

The spread of the disease was soon linked to the exchange of infectious body fluids: at first, seminal fluid and then blood. The CDC made its first etiologic statement in a presentation to the US Congress in December 1982 followed by a report 3 days later in the *Morbidity and Mortality Weekly*. It wrote that the “etiology of AIDS remains unknown, but its reported occurrence among homosexual men, intravenous drug abusers, and persons with hemophilia A suggests it may be caused by an infectious agent transmitted sexually or through exposure to blood or blood products.” It cited a case in an infant who had received blood platelets from a donor later diagnosed with AIDS and introduced the term “transfusion-associated,” which was used from then on.²

Misinformation

Fear of the new disease now spread as a fear of blood, for both receivers and givers. Patients needing transfusions demanded the blood be from family members, trusted friends, female donors, or even themselves. Television features that were reporting on any aspect of the new disease opened with setup pieces showing blood being collected for transfusion and being transfused. The press recalled a relatively unused word and described “tainted” blood. Newspaper cartoons graphically linked AIDS to blood.

To the media and to the public, there was an early confusion about the changing risk statistics. The confusion was between the risk per blood recipient who ordinarily would receive several donor units of whole blood or its components vs the risk per donor unit collected. More complex was the risk from commercial blood fractions, chemically separated from pools containing plasma sometimes from a thousand donors.

Despite the internal accuracy of CDC reports, there were problems. Newsworthy people who did not wish to be known as being homosexual or drug abusers seized upon a “history” of exposure to blood as a socially acceptable explanation for their AIDS. Because health matters in the United States are in the jurisdiction of each state, reporting was easily skewed. Reports could originate from almost any local jurisdiction with transmission to the CDC

by State health offices only after the patient’s name was removed. When later the CDC did obtain special permission to investigate data submitted on “transfusion cases,” it found that of the 97 patients that it was able to trace, 6 had never been transfused.³ In Florida, special AIDS privacy laws prevented both blood centers and the State from exchanging the names of dangerous donors, blocking further follow-up that could have been done for patient protection. Some states would not report HIV findings to the CDC until the definition of AIDS was broadened in 1993 to include patients with low cell counts. That made a state eligible for more of the federal funds earmarked for AIDS.

THE POLITICAL BLAME GAME

Against that background, transfusion became a significant and daily subject for alarm. Doctors and politicians alike were accused of delivering disease instead of preventing it. Globally, some governments found it expedient to emphasize the spread of AIDS by blood transfusion rather than to recognize the existence of other societal practices at major fault.

The policy problems of AIDS and blood throughout the world were considered in a 1999 book *Blood Feuds: Aids, Blood, and the Politics of Medical Disaster*. It gathered the talents of academics, political, and social scientists; attorneys; and philosophers who reported on 8 industrialized countries.⁴ All authors had special expertise and experience, knowledge, and opinions about AIDS in the countries about which they wrote. They were writing about events from a societal perspective, often gleaned from journalism reports and prior analyses. In this report, I have drawn heavily on that retroanalysis, but I write also from the experience and viewpoint of a physician with responsibility for day-to-day provision of blood to patients during the time that the US crisis was unfolding.

My review does not address the overall problem of AIDS as a disease, nor its treatment, nor its tragic effect on its victims. It is rather a report on how the blame on blood was handled differently in 4 industrialized democracies: the United States, France, Japan, and Canada. They had all entered the 1980s with a totally volunteer blood donor base for provision of transfused blood components but also relied heavily for hemophilia A therapy on

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