

Social Dimensions of an Infectious Disease

William A. Rushing

THE AIDS EPIDEMIC

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Preface

Infectious diseases had been declining for many years in the United States when an apparently new infectious disease, acquired immune deficiency syndrome, or AIDS, suddenly appeared in the early 1980s. This is the most serious disease to appear in modern times, and as of this writing, neither vaccine nor cure is in sight. From a sociological point of view, AIDS is perhaps the most important disease in American history, and it is certainly one of the most important in all history.

Although most scientific experts on AIDS agree that a virus called human immunodeficiency virus (HIV) is the basic cause of AIDS, social factors are significant in the extent to which and the way in which the virus is transmitted. Some populations with certain social and cultural characteristics have much higher rates of HIV-AIDS. To date in the United States, HIV-AIDS has been predominantly a male disease and is disproportionately concentrated among male homosexuals (gays), injecting drug users (IDUs), and some racial-ethnic groups. A virus obviously does not discriminate against people because of their sexual orientation, drug use, or skin pigmentation. Rather, social and cultural factors explain why HIV-AIDS has become so prevalent in these populations. They also explain why HIV-AIDS in sub-Saharan Africa is far more prevalent than in the United States and why it is about evenly distributed between males and females in Africa. Furthermore, that the epidemic has slowed in the United States in recent years but not in sub-Saharan Africa (and other developing regions) also points to the role of social and cultural factors in the transmission of HIV.

Sociologically, one of the most significant aspects of any disease is its social meaning as distinct from its medical meaning and how the former affects the way some people react to those who have the disease. The social meaning of and societal reactions to HIV-AIDS have been unusually negative and extreme. Ostracism—the sociologist's favorite topic—has been common; persons who have HIV-AIDS have not always been treated as persons with a medical pathology but rather as moral deviants and outcasts. Although experts agree that education and prevention programs would slow the spread of HIV in the United States, the social meaning of the disease leads some people to oppose those very programs. At the same time, others have charged the government with refusing to support research and prevention programs because government officials do not care about the plight of the populations

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in which HIV-AIDS is most prevalent. Some gays and African Americans have even claimed that HIV-AIDS is a genocidal plot against them. Such extreme reactions are simply not in keeping with the way a civil society based on humane and rational values typically reacts to disease.

These and other social aspects of AIDS have been topics of myriad news columns, television programs, technical reports, books, and journal articles since the mid-1980s; the social aspects of HIV-AIDS have been analyzed more in this short time period than have the social aspects of any other disease in history. Recently, however, concern about AIDS has begun to decline. The viral cause of AIDS is now known, the major types of high-risk behaviors have been identified, the rate of increase of new AIDS cases is slowing (at least in the United States), the ostracism of people with AIDS has become milder in tone, and the demonstrations and accusations by AIDS activists have been muted. Hence, *New York Times* reporter Jeffrey Schmalz, who died from AIDS, wrote in a posthumously published *New York Times Magazine* article ("Whatever Happened to AIDS?", November 28, 1993) that AIDS was old news and that interest had waned. The social crisis of AIDS had been analyzed and reanalyzed; there seemed to be little new to say.

Why, then, in the mid-1990s, publish a book on social aspects of AIDS? Such a book is needed because this disease is still not very well understood sociologically. Despite all the attention that social factors in the etiology of AIDS and the societal reactions to the AIDS epidemic have received, their study in terms of the concepts and principles of sociology has been extremely limited. True, scientific experts agree that to attribute the cause of AIDS to a particular virus, while medically valid, oversimplifies and ignores the fact that certain behaviors associated with particular groups and populations are major factors in the etiology of AIDS. But such behaviors are anchored in the cultural norms and social institutions of those groups and populations. High-risk behaviors for transmitting HIV have not been examined extensively from this perspective.

Societal reactions to the AIDS epidemic are also anchored in cultural beliefs and social institutions. Modern society is indeed more civil than its predecessors, but the social forces typical of past societies are latent in the structure of today's society. When an epidemic like AIDS appears, such forces emerge and lead people to act as their ancestors did to previous epidemics. No less than the etiology of HIV-AIDS, the societal reactions to the AIDS epidemic pose important social problems that are as vexing as are the medical aspects of the disease.

By examining the two major social dimensions of HIV-AIDS—its social etiology and societal reactions to the disease—with concepts and principles of sociology, I show how HIV-AIDS is more complex and socially embedded than many have assumed. Although I bring little original evidence to bear on the epidemic (experts on HIV-AIDS and much of the public are aware of

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most of the basic facts about the disease), I hope that by interpreting these facts in terms of sociological concepts and principles, I can shed a different light on HIV-AIDS. The insights that such an interpretation brings can provide a broader understanding of HIV-AIDS and the course the epidemic has taken. Perhaps these insights will also help clinicians, public health officials, policymakers, and AIDS activists in dealing with the problems of this terrible disease.

-William A. Rushing

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W.A.R.

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Tables and Figures

Sociology and AIDS

In the early 1980s an apparently new disease, acquired immune deficiency syndrome, appeared in the United States and spread rapidly. Almost all biomedical scientists believe AIDS is caused by a virus; for most patients the infection is lethal. Because most scientists also agree that an effective vaccine or cure for the disease is not imminent, many future AIDS deaths are inevitable. The disease has already taken a heavy toll in the United States. According to the Centers for Disease Control (CDC), reported cases of AIDS rose from 295 in 1981 to almost 42,000 in 1991, an increase of more than 14,000 percent, and reported AIDS deaths increased from 126 to more than 30,000, an increase of more than 23,000 percent (CDC, 1993a:17). In the United States AIDS is now the leading cause of death for men aged twenty-five to forty-four years of age and the fourth leading cause for women twenty-five to forty-four (CDC, 1993d). The AIDS epidemic is the most serious epidemic to appear in the United States since the Spanish flu of 1918, which took many lives but lasted only a few months. The AIDS epidemic continues.

The disease first became evident among male homosexuals and intravenous drug users, and in the United States it remains disproportionately concentrated in these two populations. However, in most developing countries AIDS is found spread throughout the entire population; death tolls of holocaustal proportions seem likely. According to a 1992 projection of the International AIDS Center of the Harvard School of Public Health, up to 110 million people may be infected worldwide by the year 2000 (up from about 13 million in 1992), 90 percent of whom will be in Third World countries (Mann et al., 1992:3, 103, 107–108).

AIDS, The Disease

Almost all experts believe that AIDS is caused by the human immunodeficiency virus, or HIV. Usually when a person is attacked by an infectious microbe (bacterial, viral, fungal, protozoan), his or her immune system will release immunocytes to fight the infection. HIV, however, is a special kind of microbe. It is a retrovirus, which inactivates the immune system and destroys its ability to produce certain immunocytes, namely, CD4 T cells. This makes 2 Introduction

the body helpless against a variety of infections, known as opportunistic infections, that healthy persons can usually throw off. A syndrome of such infections constitutes AIDS. The syndrome includes a rare form of pneumonia (*Pneumocystis carinii*, or PCP), skin cancer (Kaposi's sarcoma, or KS), herpes simplex or cold sores (with esophagitis, pneumonitis, or mucocutaneous ulcers), candidiasis of the esophagus and trachea, blood poisoning, and infections of the brain and nervous system (CDC, 1993a:16). All persons who have AIDS do not suffer from all of the diseases, however; and resistance may be strengthened with proper exercise, rest, and good nutrition (Root-Bernstein, 1993:49–56, 359–360). In time, however, most infected persons typically suffer from several infections, the cumulative effects of which cause death.

There are two known variants of HIV: HIV-1 and HIV-2. Both variants cause AIDS, but HIV-1 appears to be more virulent and may lead to AIDS faster (Ewald, 1994:130–132). Globally, HIV-1 is also more prevalent. HIV-2 is most often found in West Africa, though sporadic cases have been observed in the Americas, India, and a few European countries (Mann et al., 1992:79, 89, 275–276). Nonetheless, for our purpose the general term HIV suffices.

HIV may vary widely from individual to individual and over time within the same individual (Ewald, 1994:125–130); it mutates very rapidly, even faster than influenza viruses. Consequently, even if an effective drug were developed for one HIV strain, it might not be effective for another. Certain drugs may suppress HIV or fortify the immune system, and hence slow the progress of opportunistic infections, but at present medicines cannot make people who have HIV noninfectious or prevent their deaths. Some biologists believe the mutating character of HIV is such that any vaccine or cure would soon be ineffective (Ewald, 1994:179–180).

HIV, ARC, and AIDS

HIV infections do not immediately result in AIDS. After infection occurs, a period variably estimated at two to fifteen years (McLaughlin, 1989:18; Anderson and May, 1992:62; Root-Bernstein, 1993:55; and Ewald, 1994:128) elapses before AIDS appears. The period from infection to onset of disease is longer than for most infectious microbes. Eventually, however, most infected persons develop AIDS-related complex (ARC), in which some opportunistic infections appear. In time, the ability of the immune system to produce CD4 T cells is destroyed, and infected persons contract various diseases; these people have "full-blown" AIDS.³ Since all persons infected with HIV do not have AIDS, in many instances the generic term HIV-AIDS is the appropriate term to use (though some writers prefer "HIV disease").⁴

Sometimes, however, it is appropriate to refer just to HIV, as in "HIV-infected person." In other instances, the term AIDS is more appropriate, as in "AIDS epidemic" rather than "HIV-AIDS epidemic" or "HIV disease epidemic." This usage is consistent with medical convention, in which an epidemic is named by the disease rather than by the microorganism that causes the disease, as in "cholera epidemic" rather than "Vibrio cholerae epidemic" or "Vibrio cholerae disease epidemic."

Almost all AIDS statistics for the United States come from CDC publications. The number of AIDS cases has increased over time, partly because the definition of AIDS has been expanded. In particular, the number of conditions that meet the CDC's criteria for AIDS changed in 1993, resulting in a substantial increase in the number of cases. However, most statistics in this book are for the years prior to 1993.

As of December 31, 1992, the CDC (1993a:17) had reported 253,448 cases since 1980, of which 171,890 resulted in death. As for the number of persons in the United States who are infected with HIV, a seroprevalence survey, in which a test is done on blood drawn from participants, conducted by the National Center for Health Statistics (NCHS) for 1988–1991 (reported in December 1993) indicated that the number could be less than 1 million (Altman, 1993), which is much less than the public and many experts had believed. Previous overestimations affected societal reactions to HIV-AIDS significantly.

A Blood-borne Disease

HIV infection occurs when an infected person's blood or other body fluid (e.g., semen, plasma) enters another person's bloodstream (Friedland and Klein, 1987; Rothenberg, 1988:286). The most efficient mode of transmission is the entry of a large amount of infected blood into the bloodstream, as in a blood transfusion. However, the most common transmission mode is through sexual intercourse, from male to female, female to male, or male to male. Sex between males is the most frequent mode of transmission in industrialized countries; sharing of contaminated syringes by drug users is the second most common mode. In developing countries sex between males and females is the dominant mode of transmission.

Infection may also occur through placental transfer to a fetus and through receipt of blood products (as in treatment of hemophilia) and when infected blood enters a person's bloodstream via skin cuts and abrasions. The latter mode is much rarer, but health care workers have greater risk because of their contact with AIDS patients.⁵ Although the virus has been isolated in saliva and tears (Fujikawa et al., 1985), the amount is miniscule, and there is no evidence that anyone has been infected from this source.

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HIV-AIDS is thus not a common "everyday" infectious disease. HIV is not transmitted through the air, like the microbes in tuberculosis and influenza. It cannot be transmitted through physical touch, like many fungal infections are. It is not transmitted in contaminated water and food, like cholera, dysentery, and typhoid fever. The virus is not transmitted by an insect, as are plague (flea) and malaria (mosquito). Even the risk from mucous membrane contact, as with syphilis and other sexually transmitted diseases (STDs), is very low. In sum, HIV cannot be transmitted through casual contact (Lifson, 1988) and is not easy to "catch" or "pick up." It almost always requires the active participation of an individual in activity in which body fluid is exchanged with one or more persons.

Scientific Disagreements

Although most HIV-AIDS experts agree that HIV is necessary and sufficient to cause AIDS, some scientists dissent.⁶ They note that cases of AIDS may exist in which HIV has not been detected and that some people infected with HIV may actually fight it off (Root-Bernstein, 1993:21–30, 49–56). Also, immunosuppression and AIDS may be due to factors other than HIV (Root-Bernstein, 1993:110–147). For example, when semen gets into the blood-stream of a sex partner, it may suppress the immune system by itself (Root-Bernstein, 1993:115–116). Nevertheless, even most critics agree that HIV is a dominant factor in AIDS even if it is not necessary and sufficient to cause AIDS. There are very few cases of AIDS in which HIV is not present (and most experts believe there are not any).

Most of the scientific disagreements concern how physiological processes are involved in the progression of HIV to AIDS rather than whether certain types of behavior are related to the transmission of HIV.⁷ Even if some of the critics are correct, their criticisms are of little consequence for understanding the social aspects of HIV-AIDS. For example, the most thorough critic of the orthodox formulation does not deny the importance of behavior, such as certain types of sex acts, that the orthodox view emphasizes (Root-Bernstein, 1993:110–147). Whether semen causes immunosuppression by itself or via HIV is immaterial to the social dynamics of risky sexual behavior and its roots in social institutions.

The Sociological Significance of HIV-AIDS

The major premise of the sociological study of disease is that, even though all diseases are medical phenomena, they cannot be adequately understood in medical (or biological) terms alone. Diseases also have social features that can be understood only in terms of sociological concepts and principles. HIV-AIDS is no exception.

The immediate cause of any infectious disease is a microorganism. However, social factors influence person-to-person transmission and may explain why the prevalence of a disease varies between populations. Thus, although HIV is the (apparent) biological cause of AIDS, social factors determine the behavior that is crucial in most transmissions of HIV and explain why some groups and populations have higher rates than other groups and populations. The major groups with high rates of HIV-AIDS are well known gays⁸ and drug injectors in the United States and men and women in sub-Saharan Africa (referred to in this book as Africa). Certain types of person-toperson contacts are common among gays and drug injectors in the United States, whereas other types of contacts are common between men and women in Africa. For this reason, most experts on HIV-AIDS agree that differences in prevalence between populations are due to differences in certain behaviors. This is a valid idea. But unless the social conditions, such as cultural norms and social institutions, that regulate these behaviors are also specified, it is a limited idea. Sociological analysis of behavioral differences between populations is generally guided by the principle that these differences are related to variations in social conditions. Such analysis seeks to understand the dynamics of the relationship between social conditions and individual behavior. The principle that behavioral differences are related to social conditions is the central principle in the analysis of the social etiology of a disease. It applies to HIV-AIDS no less than to other diseases.

One aspect of the social etiology of HIV-AIDS concerns the *emergence* of HIV. No one knows how old HIV is, but experts in infectious diseases have long believed that changes in social conditions have played a role in the origin of infectious microbes. Significantly, dynamic social changes occurred in the American gay and drug subcultures and in Africa in the 1960s and 1970s, shortly before the AIDS epidemics in these regions began. This raises the question of whether changes in social conditions may have contributed to the emergence of HIV as well as to its epidemic spread in the different populations.

Understanding the social etiology of HIV-AIDS is important to understanding where HIV-AIDS is headed. It seems clear now that the rate of increase in HIV-AIDS is slowing in the United States but continues to accelerate rapidly in Africa. These trends are obviously not due to differences in access to vaccines or medical cures. Instead, they are due to differences in the effect of social factors on the behavior through which HIV is transmitted.

Sociologically, the societal reactions to HIV-AIDS, especially during the 1980s, are as significant as the social etiology of the disease. Persons with HIV-AIDS, particularly gays, have been deserted, denied proper medical care, and physically brutalized. Children with HIV-AIDS have been prohib-