

The economics of the AIDS epidemic: Lessons from the United States

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THE AIDS epidemic officially began in 1981, when a number of physicians in New York and California described the existence of a terrible new disease that was afflicting some of their homosexual patients^{1,2}. Later epidemiological research documented cases of infection by the human immunodeficiency virus that had occurred in the United States before 1981 and in countries other than the United States³. Today, HIV infection has spread around the globe. Nonetheless, in the thirteen years since those New York and California cases, more AIDS cases have been diagnosed and officially reported in the United States than in any other country. The AIDS cases reported in the United States through 1992 accounted for 44% of all documented AIDS cases for that year⁴. Estimates of the number of AIDS cases in Africa far exceed the US figures, but many of these cases are not reported³.

Together with the large number of cases diagnosed, the research funding capacity of the United States government and the encouragement of vocal groups of people with AIDS have made the United States the predominant setting for AIDS-related research. In 1990 alone, the United States federal government spent more than \$1.6 billion dollars for AIDS-related research and control activities, including substantial funding for social and behavioural research³. More than 500 articles have been published on economic, historical and ethnographic aspects of the epidemic in the United States.

The course of HIV disease varies little, whether a case is diagnosed in the United States or in a developing country⁵. As a consequence, medical researchers around the world have been able to benefit from US investments in AIDS research. More than most other diseases, AIDS raises complex issues that cut across economics, sociology, organizational behaviour, and psychology as well as medicine. The nature of HIV transmission, the long incubation period of the virus, and the devastating impact of the illness strongly suggest that economic and other social science research is critical to understanding and ultimately conquering this disease. While at first glance the disease's economic and social implications appear to be quite different in developing and industrial countries, some of the results of the many social science research projects in the United States are relevant for Asia too. This paper describes twelve lessons learnt from such research.

Estimates of the cost of treating HIV infection should incorporate both AIDS and pre-AIDS costs

Before 1993, the clinical definition of AIDS in the United States included only those with specific symptoms of the disease. In 1993 the surveillance definition was broadened to include those with severely depressed immune systems whether or not they manifested particular symptoms⁶. Under the new Centers for Disease Control definition of AIDS, patients' HIV status and CD4 counts (a measure of immune status) alone may determine a diagnosis of AIDS. This adjustment in the surveillance definition has had a substantial impact on the number of cases reported. In New York City, for example, researchers expect a 50% increase in cases among injecting drug users because of the change in definition⁷. Outside the United States, the costs of testing for serostatus and CD4 counts may limit the effect of any broadening of the case definition, leaving many HIV-infected people with severe immunosuppression outside the official count of AIDS cases.

The US experience suggests that estimates of the cost of treating HIV infection that use earlier definitions and begin counting costs only after AIDS symptoms begin may significantly underestimate the full medical costs of the disease. Based on the pre-1993 definition, an estimated 30% of the total HIV-related costs in the United States were for HIV-infected patients who did not have symptoms of AIDS⁸. US estimates suggest that the annual costs of treating HIV infection prior to the development of AIDS symptoms are between 10 and 25% as high as the cost of treating AIDS^{9, 10} and that 40% of the lifetime per person cost of HIV infection is incurred before the development of AIDS¹¹. Estimates of the proportion of total costs incurred in treating presymptomatic HIV infection in the United States may exceed comparable estimates for other countries because a portion of the US cost of treating presymptomatic patients covers costly prophylactic drug therapies. Estimates that predate the widespread use of such therapies, however, also describe significant costs incurred prior to AIDS diagnosis for patients with wasting syndrome, lymphadenopathy, and other pre-AIDS consequences of HIV infection^{12,13}.

These studies suggest that financial estimates of the effect of HIV on the health sector should move beyond measuring the costs of AIDS alone. Especially in areas where HIV testing is not done routinely, health care costs may rise substantially before large numbers of AIDS cases have been diagnosed and before the spread of the epidemic is recognized.

Estimates of the cost of the HIV epidemic should incorporate estimates of the cost of related opportunistic infections

The HIV epidemic in the United States has been associated with a resurgence of other infections, particularly tuberculosis^{14, 15}. Tuberculosis, an airborne disease, is far more infectious than HIV³. HIV-infected patients, with their depressed immune systems, are especially vulnerable to tuberculosis. As the number of HIV-infected people with tuberculosis increases, others, even those who are not HIV-infected, run a greater risk of encountering tuberculosis carriers and becoming infected.

Tuberculosis is a costly disease. For those with non-drug-resistant strains, the estimated cost (inflated using the medical care component of the US consumer price index) of hospital care in the United States averaged \$9000 (in 1991 dollars) in one 1980 study¹⁶. Higher rates of infection, especially in populations that may not complete the course of drug treatment, raise the spectre of drug-resistant tuberculosis. Drug-resistant strains are far more difficult and costly to treat successfully. In the United States the cost of treating drug-resistant tuberculosis can reach as much as \$200,000 per case¹⁷.

Tuberculosis was almost eradicated in the United States before the beginning of the HIV epidemic¹⁷. The dramatic recent growth in cases, especially in centres of HIV infection, raises the possibility that the HIV epidemic may ignite additional subepidemics of costly infectious diseases. If HIV sets back progress in the control of other infectious diseases, the total costs associated with the virus may dwarf those that economists have computed until now.

Health planning, particularly the development of alternative care facilities, can substantially reduce the cost of AIDS care

The earliest estimates of the costs of HIV infection in the United States documented an enormous disparity between costs in the two major centres of infection, New York and San Francisco¹⁸. Costs of treatment in New York were almost twice as high as costs in San Francisco. This difference has persisted over time and cannot be attributed to differences in the characteristics of AIDS patients in the two cities. Rather, the variation

stems from the alternative treatment patterns employed in San Francisco and New York¹⁹.

The less costly pattern of treatment in San Francisco arose because local homosexual men's groups rapidly organized outpatient treatment and hospice facilities for people with AIDS²⁰. By contrast, few such community-based out-of-hospital facilities were available in New York²¹. The presence of community-based facilities in San Francisco enabled doctors and hospitals to establish patterns of care that relied on outpatient and nonhospital therapy²²⁻²⁴. Despite efforts to establish alternative forms of care for people with AIDS in New York, patients in New York still spend substantially longer time in hospital than do those in San Francisco and are much more likely to die in hospital^{19, 25}.

Even within cities, patients who have access to out-of-hospital facilities incur lower costs than those who do not. Within New York, the costs of care for injecting drug users without stable housing are significantly greater than those for similar patients with stable housing facilities²⁶. The role of social support in reducing costs is particularly evident in the case of paediatric HIV infection. Mothers infected with HIV may not be able to care for their HIV-infected babies and may leave them in the hospital. The length of stay in the hospital for these babies may be as much as four times as long as for babies born with HIV infection who have homes²⁷.

In response to the growing number of HIV-infected babies in US hospitals, health planners and community groups have developed special foster care facilities^{28, 29} for HIV-infected babies. Like the alternative treatment and care facilities developed for adults in San Francisco, these foster care facilities for babies have the potential of reducing the cost of care for HIV patients without diminishing the quality of care provided. These innovations highlight the importance of health planning and interorganizational coordination in developing cost-effective forms of care for people with AIDS.

The cost of AIDS control should be incorporated into estimates of the economic effect of the epidemic

The costs of treating AIDS are so high that investments in prevention and control will frequently be cost-beneficial. The costs of these investments, however, are real resource costs associated with the epidemic. In the United States, these costs include the cost of AIDS research, which in 1991 came to \$805 million at the National Institutes of Health alone³⁰, the costs of tracking the disease, which in 1991 came to \$509 million for the Centers for Disease Control³, the costs of educational campaigns, which in 1991 totalled \$700 million for federal and state educational programmes³¹, and the cost of precautions to avoid HIV infection. In

health care settings, the cost of implementing the precautions recommended by the federal government amount to more than \$800 million per year³¹.

These budget items by no means exhaust the range of national efforts for AIDS prevention and control, but these alone, taken together, cost about as much as the lifetime cost of treating 23,000 HIV-infected people¹¹. Exclusion of the costs of prevention and control from estimates of the cost of the epidemic leads to significant understatement of its economic impact.

Concentrating AIDS care in a few centres may improve quality and reduce cost

A series of recent studies in the United States have examined the relationship between hospitals' experience in treating HIV patients and the quality of outcomes achieved. In keeping with results from studies of other diseases, researchers have found that hospitals with more experience in treating AIDS generally achieve better results³². Mortality rates for patients with a variety of AIDS-related opportunistic infections are significantly lower in hospitals that have treated many AIDS patients^{33, 34}. While these studies do not measure the cost of care, other studies have examined changes in the cost of care over the course of the epidemic. These studies suggest that as health providers and health systems learn about HIV the cost of treatment declines. In particular, over a period of time, providers are more likely to have access to and to treat HIV using outpatient treatment facilities¹¹.

The need for special precautions to lessen the risk of HIV transmission to health care workers also supports a policy of concentrating care in a few centres. Precautions against transmission may involve the use of special equipment and procedures. The fixed costs of acquiring new equipment and adopting new procedures in a hospital may be considerable³⁵. Concentrating cases can reduce the average cost of precautions per case. Concentrating cases may also enhance the value of these precautions by encouraging health care workers to cooperate with safety guidelines. Some evidence suggests that compliance with safety precautions is greatest in areas with the highest prevalence of AIDS cases – where medical workers are at highest risk³⁶.

Concentrating facilities for care of HIV patients in a few centres may improve quality and reduce costs. As physicians gain experience with the disease, they may choose fewer, more effective treatments, they may have a better sense of when to discharge a patient from hospital, and they may know of more alternative facilities that can take patients. Gains from experience across hospitals, though, do not seem to translate into gains from concentrating patients into dedicated units within hospitals. Experiments with dedicated AIDS units

show little improvement in costs or quality of care relative to patients cared for in other parts of the same hospital³⁷.

The possible presence of economies of scale in AIDS treatment suggests that careful health facility planning can reduce the epidemic's costs and suggest a possible source of upward bias in the existing estimates of AIDS costs. Simple linear extrapolations from the cost of treating the first few cases encountered in a country may greatly overstate the full cost of well-organized treatment.

Health manpower planning should incorporate the effects of HIV on provider recruitment

Health care providers who serve patients with HIV infection risk exposure to the virus. Unlike other conditions to which health providers may become exposed, HIV infection cannot be cured or avoided through vaccination. Given the devastating impact of HIV transmission, health providers' reluctance to treat patients with the disease is not surprising.

Problems in personnel recruitment have increased over time. Early in the epidemic, awareness of the risk of transmission was limited³⁸. Furthermore, medical personnel may have been interested in being on the forefront of treatment of a new disease. Since then, despite costly precautions to avoid HIV transmission, some medical workers have been infected through occupational exposure³⁹. As the number of cases and perceptions of the risk of transmission have increased and the lure of medical innovation has diminished, medical personnel recruitment has been affected³⁸.

In recent polls, many doctors express an aversion to treating AIDS patients and state that they would not care for these patients if they had a choice^{40, 41}. Hospitals with large AIDS caseloads have had trouble recruiting medical staff⁴². Similarly, interest in specialties that now involve caring for many AIDS patients appears to have declined⁴³.

The cost implications of recruitment difficulties can be monetized as the compensating differential need to attract providers to care for HIV patients. Studies have not yet estimated the magnitude of this compensating differential, but polling data and recruitment evidence suggest that it may be substantial. Health planners should take into account the possibility that recruitment of personnel will become increasingly difficult and costly as the epidemic progresses.

Prevention efforts should be targeted to high-risk groups and areas

The first cases of AIDS reported in the United States were among homosexual men and intravenous drug users. Thirteen years later, these two groups continue to

account for about 80% of all newly diagnosed cases⁴⁴. The epicentres of the epidemic in the early 1980s were San Francisco, Los Angeles and New York City. Today, these three cities account for almost a quarter of newly diagnosed cases. Although the epidemic has spread beyond the original risk groups and to other regions of the country, it remains heavily concentrated in the populations and places where it began. The growing number of cases among heterosexuals can often be traced back to contact with a member of the traditional risk groups. This epidemiological pattern suggests that the benefits of prevention and control efforts targeted at traditional risk groups may persist over time.

A growing body of evidence also suggests that prevention and control strategies targeted at lower risk groups may be quite ineffective. Despite considerable concern over the possible spread of the AIDS epidemic in the United States to groups other than homosexual men and injecting drug users, few changes in the behaviour of low-risk groups have been documented. While behaviour changes rapidly in response to perceived increases in risk in local communities, perceptions of general risk do not seem to affect behaviour⁴⁵. Changes in behaviour have been greatest among urban homosexual men, followed by injecting drug users. Lower-risk groups, particularly young heterosexuals, although they are quite well-informed about HIV, show few changes in behaviour in response to the epidemic⁴⁶. Costly efforts to encourage changes in behaviour in these groups, including public educational campaigns, have had limited effects on behaviour. While some increase in condom use among heterosexuals has occurred, most of this change appears to have followed early media reports about the epidemic. US Surgeon General Koop's public mailing of AIDS information to all American households in 1988 did not affect measured risk behaviours significantly⁴⁷.

Most educational campaigns for AIDS prevention among heterosexuals in the United States encourage condom use. Condoms are inexpensive relative to income in the United States, and in some schools and universities are provided free. Nonetheless, as recently as 1988, fewer than 20% of never-married women in the United States who reported using contraception used condoms⁴⁸.

These results suggest that the nonmonetary costs of changing sexual behaviour are high. Unless people perceive a significant risk of infection, they may rationally choose not to change their sexual practices³¹. Combined with the evidence that the epidemic has remained concentrated at its original sites, the reluctance of those at low risk to change their behaviour suggests that the most cost-effective approach may be to target prevention and control efforts at high-risk groups.

Groups that face a high risk of infection will change their behaviour if they have information and opportunity

In 1986 researchers forecast that 87,000 new AIDS cases would be diagnosed in the United States in 1991. The actual number of cases diagnosed in 1991 missed this mark by 41,000. The reduction in AIDS incidence by 1991 occurred because groups at high risk of HIV infection had made massive changes in their behaviour to avoid infection⁴⁹.

Estimates of behaviour change suggest that news about AIDS led to a rapid and profound change in the sexual behaviour of homosexual men⁵⁰. One report finds that the proliferation of information about the epidemic resulted in a threefold to fourfold decrease in rates of high-risk sex among this group⁵¹. Studies of injecting drug users also find evidence of substantial changes in behaviour. Towards the end of 1983, drug users had reduced needle-sharing and increased their efforts to clean needles between injections⁵².

These results suggest that even before major government campaigns, individuals who faced a significant risk of infection took steps to reduce their vulnerability. For homosexual men, these changes in behaviour led to a notable reduction in the spread of the disease. By 1991, cases among homosexual men were about one-third lower than had been projected⁴⁹. Unfortunately, behavioural change among injecting drug users had smaller effects on the spread of the epidemic among this population. Effective behavioural change for members of this group required access to costly goods and services – drug treatment programmes, bleach, clean needles – that may have been unaffordable given their incomes. Public funding for programmes aimed at injecting drug users has been mired in controversy and slow to respond to the epidemic⁵³.

Evidence from high-risk groups in the United States suggests that information about HIV can spread more rapidly than the virus itself. People who perceive themselves as vulnerable to infection do make efforts to change their behaviour. For many, however, public support is necessary if these behavioural changes are to be translated into reductions in infections.

Complacency is dangerous, behaviour changes are difficult to maintain

While the evidence of changes in behaviour among high-risk groups is encouraging, some recent studies document increases in dangerous behaviours among these groups. These studies are the mirror image of those that found reductions in high-risk behaviour early in the epidemic. Then, as the perceived risk of infection increased, vulnerable populations changed their behaviour. Now, as the perceived risk of infection

declines, vulnerable populations show signs of resuming their preepidemic behavioural patterns^{31 50}.

High rates of risky sexual behaviour have been documented among homosexual men in small cities, where AIDS rates are low, and among young homosexual men⁵⁴. The HIV epidemic has not led to a fundamental change in sexual habits. Rather, homosexual men in communities that have not been severely affected by the epidemic, whether because they are geographically isolated or because they include men who have come of age since 1981, continue to practice high-risk sex. Some studies also document reversions to high-risk behaviour among homosexual men who had changed their behaviour earlier in the course of the epidemic. These studies are consistent with the view that the nonmonetary cost of safe sex is high, and that only those who perceive a significant risk of developing AIDS will find that the benefits of changing behaviour outweigh the costs. Any reductions in high-risk behaviour should be cheered, but health planners should beware of the potential for recidivism.

Community participation should be encouraged

Among both homosexual men and injecting drug users, significant information dissemination leading to behaviour change occurred through community action. Community organizations sponsor educational activities and take an active role in marshalling public funding for AIDS research and prevention²⁰. The epidemic's focus on traditionally marginalized groups, who may not trust public authorities, makes the role of community groups in education especially important.

Community organizations have also been at the forefront of treatment innovations. The development of out-of-hospital facilities for the care of AIDS patients was largely the work of voluntary community groups. Especially in the first decade of the epidemic, volunteers provided a significant portion of the care patients received²⁰. Community organizations and voluntary labour have substantially reduced the cost of preventing AIDS and caring for AIDS patients in the United States.

Some researchers have expressed concern that the potential of community organizations and volunteers may soon be exhausted²⁰. These organizations draw staff and resources from the very communities that have been hardest hit by the epidemic. As more community members succumb, the burden on those who remain healthy may become excessive. Without the participation of community organizations, the quality of educational interventions and of care offered to those with AIDS will suffer, and the monetary costs of these activities will rise.

The US experience suggests that community groups can contribute greatly to the task of coping with the HIV epidemic, but that these groups can become exhausted.

Health planners should encourage the development of community groups and their participation in AIDS prevention and care. They should also provide both encouragement and tangible support to these groups as the epidemic continues.

Efforts to reduce stigma and discrimination against people with HIV can reduce the cost of the epidemic

HIV is not infectious in ordinary workplace or educational settings. Unfortunately, fears and misconceptions about the disease abound. In 1987 one-third of Americans polled believed that an HIV-infected worker should be fired and one-quarter stated that they would not work with a person who had AIDS³. Parents throughout the United States have tried to keep HIV-infected children out of schools⁵. Such attitudes may lead to unwarranted and costly dismissals of productive people and to increased costs for child care and education. On average, HIV-infected people carry the virus for ten years before manifesting symptoms. The present value of foregone income over the remaining healthy lifetime of an average American male full-time worker who loses his job when he becomes HIV-infected is almost \$250,000 (based on mean money income in 1991 of year-round, full-time male worker discounted at 5% over ten years⁵⁵. Estimate of healthy life expectancy is reported in ref. 3.).

Efforts to educate the general public about the realities of HIV may have succeeded in reducing the stigma associated with AIDS⁵⁶. By 1991, the number of people reporting that they believed an HIV-infected worker should be fired and that they would not work with a person who had AIDS had dropped to one in five and one in six, respectively³. Nonetheless, considerable stigma and misinformation remain⁵⁷. Information campaigns designed to reduce discrimination may pay off in better use of productive resources.

Economic policy should redistribute the burden of HIV costs from affected regions to the nation as a whole

The lifetime cost of treating HIV infection in the United States is more than \$100,000 (ref. 11). The almost 145,000 people who contracted AIDS in the United States during the 1980s were predominantly young, productive men with many years of earnings ahead of them⁴⁴. Nor are there readily available substitutes for these men. During the last half of the 1980s, unemployment rates in the United States for men over 20 averaged just over 5% (ref. 56). Despite the high cost of treatment, the productivity of those who contracted

AIDS and the relatively inelastic supply of labour in the United States, the epidemic has not had a devastating effect on the macroeconomy of the nation as a whole. The estimated lifetime federal and state tax revenue losses associated with the 35,000 Americans who died in 1992, for example, amounted to only 1.5% of the revenue of the federal government in that year^{1, 5, 44}. The medical care costs of AIDS account for a similar portion of total United States health expenditures¹³.

The relatively benign effect of the epidemic on the macroeconomy of the nation as a whole contrasts with its devastating effects on particular regions, especially on communities within these regions^{18, 20}. In New York City and San Francisco, the total number of AIDS cases diagnosed since the beginning of the epidemic amount to more than 1 case for every 150 current residents⁴⁴. In some New York City neighbourhoods, the number of AIDS cases diagnosed in the 1980s amounted to one for every 55 residents²⁰. The costs of treatment have wrecked the finances of local hospitals and forced state policy-makers to make difficult decisions about resource allocation^{20, 58}.

The nature of transmission of HIV suggests that the epidemic will remain concentrated in particular areas of the country and in particular communities. The gulf between the ruinous effects of the epidemic on these areas and communities and its less severe effects on the United States macroeconomy highlights the importance of redistributive policies in coping with the epidemic. Effective policies will help these communities bear the epidemic's social and medical costs and, through prevention and control measures, reduce the spread of the epidemic to other areas. Thus, both compassion and self-interest dictate that nations assist those areas suffering under the weight of the epidemic. At least in the United States the economic effects of the epidemic spread across the nation as a whole will easily permit such redistributive actions.

Conclusions

Economic and social research in the United States can improve our understanding of the epidemic in other parts of the world. In terms of measuring the costs of the epidemic, United States research suggests that conventional methods of accounting may overestimate some aspects of costs by failing to recognize cost-saving methods of care, including outpatient therapy and treatment centres, that may develop as the epidemic progresses. It also suggests that many measures of economic impact often seriously underestimate the costs of the epidemic by failing to include pre-AIDS costs, the costs of related opportunistic infections, the costs of HIV prevention and control, and the increased cost of recruiting medical personnel. American research

provides cause for both hope and alarm in terms of HIV prevention. High-risk groups, particularly those in active and well-supported communities, have reduced their levels of dangerous behaviours remarkably quickly. Furthermore, educational efforts may be effective in reducing the level of discrimination people with AIDS encounter. By contrast, reversions to risky behaviour are common even in groups that had succeeded in changing their behaviour, and groups that perceive themselves to be at low risk have hardly responded to the threat of AIDS. Perhaps the most important lesson of the United States experience is that the effects of the disease are highly localized. National policy must be targeted at discrete, severely affected communities.

Lessons from the United States may be valuable. At the same time, one must recognize that the United States epidemic differs substantially from that in other countries. Most people with AIDS in the United States are homosexual men and drug users. Prostitution and heterosexual sex are not important vectors of transmission in the United States. The structure of economies and labour markets varies profoundly among the three major regions of HIV prevalence: the United States, Sub-Saharan Africa, and Asia. Cultural factors, including the role of community organizations and social structure, differ immensely by country, and these play a critical part in determining how quickly the spread of the epidemic can be arrested and how much it will cost to care for those who become ill. These differences may diminish the transferability of United States knowledge on the economic and social effects of AIDS, but as the epidemic rages, it makes sense for researchers throughout the world to glean what they can from each other's work.

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