AIDS AND US : ARE WE FAILING TO PREVENT A HIGHLY PREVENTABLE DISEASE?

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Figures from the Ministry of Health (1) indicate that from 1985 to 1991, only 95 persons were found infected with the HIV virus in Singapore, and 33 of them contracted AIDS. In a worldwide scenario, the Singapore rate of AIDS cases has been very low, amounting in 1990 to 0.845 per 100,000 population in contrast to significantly higher AIDS case rates in many countries. For example, the World Health Organization reported that in 1990 the AIDS case rate was 69.2 per 100,000 in the United States, 24.83 in France, and 14.54 in Australia, to mention but a few instances (2).

Thus, you may wonder, why should we worry about the spread of AIDS in Singapore? I suggest two fundamental reasons. First, it has been amply documented by infected cases around the globe during the past decade that AIDS makes no exceptions; it is a disease that does not discriminate between rich or poor, white, brown, yellow or black people, men or women, young or old. Every one is a potential victim. Second, although AIDS is highly preventable because it is linked to risk-taking behaviour and private choices, paradoxically, for the same reason communities everywhere are failing to overcome some major obstacles to its prevention. I will outline the major obstacles found in other countries, and conclude by pointing out their relevance in the context of Singapore.

MAJOR OBSTACLES TO AIDS PREVENTION

The battle against AIDS is fought on two fronts, the medical laboratory and the community. Apart from the obvious medical enigma posed by the deadly AIDS virus and the serious difficulties faced by medical scientists in finding an effective vaccine, there are two other types of obstacles to AIDS prevention that require the immediate attention of social scientists and policy makers. Both types are **social** rather than medical obstacles and the battlefield where they are fought is the community. The first type refers to individual behaviour. The second type lies in the realm of social policy.

Individual behaviour

Individual behaviour related to AIDS involves three main aspects, the person's private choices, the "not me" syndrome, and the concept of stigma. In the struggle to contain the spread of AIDS, the modification or change in these aspects of individual behaviour represents a formidable challenge. In contrast to numerous disease affecting humankind over the ages, a person's private choices in sexual behaviour and drug abuse put him or her in direct risk of contracting AIDS. Although there is a proportion of patients infected through blood transfusions—the highest recorded in Japan among haemophiliacs who account for 74% of the total cases—and babies infected at birth, the overwhelming majority of HIV infected patients and AIDS patients worldwide have contracted the disease through sexual contact or the use of infected needles for intravenous drug abuse(3). This fact has been known and conveyed to target populations everywhere during the past ten years but, with few exceptions, people at risk continue indulging in their private choices.

This trend is reinforced by the "not me" syndrome. That is, people confronted with evidence of the AIDS danger are inclined to believe that AIDS attacks other people but that it will not happen to them. Denial is a common response to actual or potential personal problems. The "not me" syndrome is frequently found among people who are taking the first steps into the path to addiction—be it gambling, alcohol, or drugs—as well as among healthy people who are asked to consider preventive measures against cancer, heart disease or other serious diseases.

Completing the picture of individual behaviour obstacles to prevention is the concept of social stigma. During the first half of the 1980s, AIDS was essentially perceived as "a disease of deviants"(4). Today, people still differentiate between patients seen as "deviants" and **innocent** victims of AIDS(5) such as babies, haemophiliacs, medical persons infected by patients' blood and people infected by their spouses. Still, "innocent" victims or not, AIDS patients face social stigma—rejection or ostracism suffered by persons who have to live with certain attributes deemed negative, repulsive or dangerous by people around them. The threat of social stigma is a powerful deterrent to seeking medical advice, or if medical diagnosis is known, the fear of social stigma precludes the patients' disclosure of their HIV infection to relevant people such as employers, colleagues, school authorities, classmates, neighbours, friends and more, importantly, to the crucial persons in this tragedy, their sexual partners or their spouses. Triggered by the fear of social stigma, the extreme reluctance and even hostile refusal on the part of a HIV infected person to reveal his or her sexual partners or to inform the spouse, constitutes a major barrier to containing the spread of AIDS.

Yet, the fear of social stigma is not unwarranted. Dramatic cases of rejection - AIDS patients have lost their jobs and their medical insurance, and have been denied their right to attend school, and even their right to live in the neighbourhood of their choice - have been reported in newspapers in several countries. Cases like these came to the public light in the United States because some courageous individuals confronted such segregation by taking legal action. People who apply social stigma are also moved by fear. Considering that there is no known cure for AIDS thus far, the social stigma attached to AIDS patients is a defense mechanism used by healthy people to prevent or minimize physical contact, much along the lines of the ancient fear of leprosy and the fear of the bubonic plague among Europeans in the 16th Century(6). As more accurate information on the modes of AIDS transmission is conveyed to the population, social stigma may take milder forms or may diminish substantially.

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Interestingly, the AIDS epidemic has brought to light a very important aspect of human relations, the role of the family, that had been overlooked during the later part of this century, especially in developed countries. It appears that, as a result of the community's rejection, the family has become the most reliable support group for AIDS patients in developed countries. Most of the time, the family's response and moral support counterbalance the social stigma suffered by AIDS victims. The positive response of the family must not obscure the serious difficulties faced by the caring family members. The tragedy of AIDS is shared by the parents, siblings and spouses who, in the case of most AIDS victims, often have to cope simultaneously with the news of the patient's homosexuality or bisexuality, promiscuity or drug addiction, and with the grief of the painful and dramatic death sentence that AIDS represents for their loved ones. It is thus essential to include the immediate family member(s) in any official or unofficial provisions of counselling, medical and economic aid to AIDS victims. This point brings me to the discussion of the second type of obstacles, those concerning social policy.

Social Policy

The three individual behaviour obstacles just discussed—the person's private choices, the "not me" syndrome, and the concept of social stigma—are closely related to matters of social policy. Social values concerning personal privacy and the individual's rights, the belief that bad things such as AIDS are more likely to happen to other people, and the tendency to see AIDS as a disease of deviants, are values affecting both individual and collective behaviour. Social policy, that is, the rules by which communities live and organize themselves, reflects such values. Four aspects of social policy are of particular interest in the discussion on AIDS prevention. These aspects are the government's role in (a) the screening of blood for transfusion; (b) mandatory testing for HIV; (c) reaching sexual contacts of HIV infected persons and AIDS patients; and (d) educational campaigns.

Screening of donated blood

A major lesson in government intervention should be learned by the disastrous judgement errors made by policy makers in the United States and France concerning the screening of donated blood. These two countries are by no means the only ones where fatal errors have been committed, but their international prominence and the detailed information available make them very good examples of things to avoid.

Pence's(7) description of the events preceding the mandatory testing of the blood supply in the United States is highly educational. Although the Centers for Disease Control (CDC) had proposed the screening of donated blood in 1981, it was only until 1985 that the CDC's proposal was taken seriously. This delay resulted in a situation whereby "probably 1 million units of HIV-infected blood were transfused between 1982 and March 1985". Consequently, in 1990 "as many as 80% of haemophiliacs are HIV-positive"(8). As an American expert in medical ethics, Pence's analysis of the overall situation in his country is revealing. He laments,

> This is tragic. Here is a disease which had 100,000 cases by 1990, with nearly 300,000 cases predicted by 1993. Yet the government still have not begun a coordinated attack with a real leader (9).

Other experts have also blamed strongly the government in the United States(5,10,11) and governments in other countries(12), for their slow reaction in taking effective steps to confront the AIDS epidemic, including the screening of donated blood. In terms of the influence of social stigma upon social policy, some American writers suggest that the key reason for the slow reaction of their political leaders to the AIDS epidemic is "the thinly veiled feeling that those who acquired the virus are getting what they deserved"(5,13).

An example of inadequate social policy towards AIDS prevention motivated by a collective episode of the "not me" syndrome, is France. For many years the French officials did not believe that their national blood supply had a serious risk of HIV contamination as in the case of the United Sates and other countries. France is now facing a public outrage after the disclosure of transfusion-related HIV infections caused by official negligence in the management of the national supply of donated blood. According to press reports (14,15), three former officials, the former director of the National Blood Transfusion Centre, the former director-general of the Health Ministry, and the ex-director of the National Health Laboratory, were charged with criminal negligence for "failing to ensure that the nation's blood supply was screened for the deadly virus." It is estimated that 400,000 people in France have the transfusion-related HIV infection; about 1,200 French haemophiliacs are infected; and 200 more have already died of AIDS "since receiving transfusions of contaminated blood before 1985".

Mandatory testing for HIV

Technically, mandatory testing for HIV could take various forms such as "premarital testing, pre-admission testing in hospitals, pre-insurance testing, and pre-employment testing"(4). But the issue of mandatory testing for HIV infection is a value-loaded or ethical dilemma in many countries. It has to do with the perceived conflict between the individual's rights and the rights of the community. A good illustration is provided by the case of the United States. In 1988, three well-known American researchers presented the American dilemma in this manner:

> ... there is considerable disagreement over how to protect the civil rights of people with AIDS, people infected with the AIDS virus, and uninfected people in high-risk groups while at the same time fulfilling another legitimate function of government—protecting public health(16).

The medical profession's code of ethics approves "the ethical obligation to protect others, even at the expense of interfering with the patient's liberty and privacy"(17) but under certain conditions. About AIDS, as mandatory testing for HIV involves a high probability of "a high number of false positives," Jonsen, Siegler and Winslade–three clinical ethics experts—assert that "the possibility of harm to the reputation, employment, and insurability of individuals is serious. Thus, the proposed policy [mandatory testing for groups of people]... is reprehensible." Referring to the case of a school board considering mandatory testing for HIV for all teachers to prevent the spread of AIDS, these experts recommend that "health professionals should not cooperate with school board policy"(18). The same argument—high number of false positives in the ELISA and other currents tests—against mandatory testing is also offered by other experts. They feel that in addition to causing unnecessary anguish to persons incorrectly labelled HIV-infected, and bringing upon them and the real HIV positive cases the harsh prejudice of society, the individual's right to privacy is violated by mandatory testing(19).

Finding the ethically correct balance between the rights of individuals and those of the community, has been a keen preoccupation of Eastern and Western civilizations since antiquity. Today, the AIDS epidemic has put that debate in the context of life and death. In his book, **On Liberty** published in 1859, philosopher John Stuart Mill provides some useful thoughts on this dilemma. The essence of Mill's position is that:

> The only part of the conduct of anyone, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute (20).

Mill's principle is concordant with the medical ethical obligation to protect others and with the acknowledged duty of governments to protect public health. Yet, the lack of agreement and decisive government action are rooted in a twofold problem: how to implement the principle of community protection from harmful individual behaviour, and what should society do through social policy and other collective decisions, with those found to be HIV-infected.

Concerning the first aspect—and in addition to the strong opposition of interest groups wielding the banner of individual rights—one of the major obstacles to the implementation of public health protection is more technical than social, namely the current experimental nature of screening tests and vaccines. The available tests still yield a worrisome level of false positive results.

The second aspect is basically social and ethical: if mandatory testing is implemented, how should we deal with those found to be affected by the disease? As Pence suggests, it is important to avoid the prejudicial goal of segregating persons found to be HIV positive(21). Effective social arrangements involving medical care, counselling, public education and other social services need to set up along the lines of equity and social justice. Some experts support mandatory testing for specific groups such as blood donors, pregnant women and prostitutes(22). Because of their nature, mandatory testing of groups such as these will increase the effectiveness of measures to contain the spread of the disease.

Contact tracing

Contact tracing involves four important aspects: "identifying, notifying, testing and counselling people who have had sexual contact (or have shared needles) with someone known to be infected"(23). The effectiveness of this procedure to contain the spread of venereal disease was recognized by public health experts during the Second World War(24). Contact tracing is fundamentally a duty of public health authorities but its implementation depends entirely on the cooperation of the infected individual in revealing his or her sexual contacts. Understandably, the implementation of contact tracing also requires mandatory reporting of infection, a procedure standardized and legitimized by international agreements with respect to venereal and other communicable diseases.

Contact tracing is another aspect of AIDS prevention where there is a perceived conflict between the individual's right to privacy and the community's right to take preventive health measures. Mill's principle on individual conduct which may harm others and the medical ethical position on protecting the public's health, support the implementation of mandatory reporting of HIV infection and contact tracing. Some experts actively recommend contact tracing not only for sexual partners but also for drug users who share needles. This is the position of Masters, Johnson and Kolodny who complain, "It seems anomalous that the single most useful means of identifying people infected with the AIDS virus (contact tracing) has been completely ignored in the nation's current response to the AIDS crisis"(23). They are referring to the situation in the United States, where opponents of mandatory reporting and contact tracing, oblivious to the success of these procedures for venereal diseases, claim that their implementation violates the individual's right to privacy. Masters, Johnson and Kolodny are not alone in defending these preventive measures. Their position is backed up by other concerned people, including some legislators. In the opinion of an American Congressman, as Pence reports:

> It is absurd and unwise public policy to trace persons with a nonfatal venereal disease and counsel them about the risks of transmission but to fail to take the same prudent steps with persons who may have acquired or carry a 100 percent fatal disease.(25)

As indicated earlier, the problems and conflicts faced in the United States concerning AIDS prevention are shared in various forms by other countries. But the American experience in combating the AIDS epidemic is better documented than most, and thus is a useful lesson for the international community. Based on the WHO estimates of the pace of spread of the disease(26), every day spent discussing the ethical aspects of AIDS prevention is a day when about 5,000 more people get infected. As a fatal communicable disease, AIDS–and HIV infection—should be approached with the same international prevention procedures applicable to other communicable diseases: mandatory reporting and contact tracing.

Educational campaigns

The final aspect of social policy that I want to discuss briefly is the role of the government in educational campaigns. Public education is mistakenly seen by some people as a panacea for public health. Campaigns to educate the public are indispensable to the objective of disease prevention but they are not sufficient to modify behaviour. If they are well planned, if they include action-oriented advice, and if they are addressed to specific target populations, educational campaigns are effective in increasing the public's level of information on the subject matter. Educational campaigns that include clear and specific information on the modes of transmission of the disease are likely to reduce the social stigma attached to that disease. But public education is not, by itself, an effective way of motivating people to take preventive action(27).

It has been repeatedly established that knowledge of health risks and of preventive measures does not guarantee a change towards preventive behaviour. But the conviction that education is the best solution persists among some policy makers and public health experts. A recent cohort study of AIDS risks compared two samples of homosexual men, one from the United States and another from Denmark, in terms of their sexual practices and their HIV status over the previous 12 months. The researchers found that "knowledge of one's own HIV status by itself did not have any significant effect" upon the men's sexual practices. This occurred for both the American and the Danish men. Also, although most of them were aware of preventive measures, only 32% of the American and 53% of the Danish homosexual men "were practising completely safe sex". Still, the appeal of education as a preventive tool continued and these researchers concluded that education should be used "to promote the need for awareness of one's own and one's partner's HIV status"(28).

The crucial point to consider is that social policy towards AIDS prevention must include educational campaigns but in combination with other measures such as screening of donated blood, mandatory reporting, contact tracing, mandatory screening of highly relevant groups such as pregnant women, blood donors, and prostitutes, and allocation of funds and manpower to continue and expand the search for an AIDS vaccine, as well as medical research on the treatment and cure of AIDS.

IS SINGAPORE DIFFERENT?

The preceding analysis has discussed the major obstacles to AIDS prevention worldwide, with special reference to developed countries in general, and the United States in particular.

I will conclude by considering the relevance of these obstacles to Singapore.

As far as individual behaviour obstacles are concerned, the "not me" syndrome and the concept of social stigma are practically universal attitudes, and Singaporeans are not different from others in this respect. Two studies conducted locally during the past four years(29-31) reported the tendency towards low perception of personal vulnerability to AIDS. When asked about the chances that they themselves "might catch AIDS," 77.2% of the 2,018 persons interviewed said "not likely at all", and 18.5% replied that they did not know. Only 41 persons, or 2% of all respondents, reported high risk behaviour — they engaged in unprotected or partially commercial sex — and just 9.7% of them indicated that their chances of getting AIDS were "somewhat likely" or "very likely"(32,33).

As expected, the presence of social stigma attached to AIDS patients is also found in Singapore. People tend to put as much distance as possible between themselves and AIDS victims. Although 80% of the 3,301 persons interviewed in 1987 said that AIDS is not transmitted by shaking hands with an AIDS patient, only 59% of them were willing to carry out this practice. A decreasing proportion of the respondents was willing to practise other forms of simple and casual contact with an AIDS patient(34).

Another feature Singapore seems to share with other countries is the tendency for the family to be the best and most reliable source of support for AIDS patients. In Emmanuel's study, 95.9% of the 3,301 respondents indicated that if a family member contracted AIDS they will help him or her "to live as normal a life as possible"(35). With the increasing trend in the Third World towards heterosexual contamination whereby spouses tend to be the major victims(36,37), this readiness to help a family member is reassuring.

The third individual behaviour obstacle found in other countries was the emphasis on the individual's right to privacy. This is perhaps one obstacle that has not become a subject of public debate and opposition in Singapore. As a communicable disease, AIDS was classified as a notifiable disease under the Infectious Diseases Act, following standard international health regulations which have been overlooked in other countries. This measure includes mandatory reporting and contact tracing as routinely applied to venereal disease.

Furthermore, to deal with the epidemic's threat, the Ministry of Health formed an Advisory Committee on AIDS in 1985. Two years later a wider network of experts and relevant organizations was brought together into two institutional bodies, the AIDS Task Force and the National Advisory Committee on AIDS. These two bodies worked out a "multi-pronged approach" planned and implemented by the Ministry of Health. This approach comprises the following measures: "routine screening of blood and tissue donors"; "guidelines for medical and paramedical personnel"; "inpatient and outpatient management of the disease"; "regular surveillance of known prostitutes"; "follow-up of infected persons"; counselling of patients, HIV carriers, their contacts, and their families; voluntary HIV screening tests; and educational campaigns(38).

It is thus evident that, compared to the hesitation and delays in government intervention and in the formulation of effective social policies often reported elsewhere, the Singaporean approach towards the AIDS epidemic has been swift and comprehensive. The characteristic social discipline of Singaporeans and their inclination to favour community concerns(39) have contributed significantly to the ease with which the above measures have been implemented. As indicated earlier, during the past decade many developed countries have been more concerned about the protection of the privacy and civil rights of AIDS patients and HIV-infected persons, and are still debating these issues.

In sum, after a decade of battling the AIDS epidemic, the international situation is still critical. Inevitably, the tragic increase in the number of victims and the great variety of groups infected show that the preventive steps taken in most countries (public education alone or in combination with promotion of condoms or "safe sex") are grossly inadequate to overcome the epidemic. It is imperative that societies everywhere examine the social reasons why they are failing to prevent this highly preventable disease. Unfortunately, policy makers and medical experts in many countries often feel that they cannot go against the outspoken opponents, or they simply do not wish to confront directly the individual and social policy obstacles discussed above.

Are we failing to prevent the spread of AIDS in Singapore? The answer must be sought at two levels, the public sphere and the realm of the citizen's private life. In their frank and clear discussion of the AIDS epidemic, Masters, Johnson and Kolodny(40) urge that we make "a personal and public commitment to prevention as a primary issue." In my opinion, we have shown a strong public commitment to prevention of AIDS as demonstrated by the existing regulations. But we may be failing in building up a strong personal commitment to prevention.

Public commitment is extremely important but, unfortunately, it is not sufficient to contain the AIDS epidemic. Private commitment is unquestionably the most crucial requirement for prevention. Yet, individual behaviour obstacles to prevention continue, particularly the "not me" syndrome and social stigma. Clearly, all recommended public health measures to combat the epidemic are being implemented. It is not unreasonable to assume that without these measures the rate of HIV infections and of full-blown AIDS cases would be much higher than the low number of infected patients we have today. But the disease has spread. As indicated earlier, the annual number of HIV-infection cases increased from 2 in 1985 to 34 in 1991, and that of AIDS cases from none in 1985 to 10 in 1991.

Although these figures are small, there is no room for complacency. Two main lessons may be learned by Singapore from the worldwide AIDS scenario and from the manner in which individual and social policy obstacles have been handled by other countries. That is, we can learn from what other countries have done or have neglected to do to build up private and public commitment towards AIDS prevention. First, the public health measures taken in Singapore to manage and prevent the disease must be continued and improved. As Singapore is in Asia (the world region predicted to be the most affected by the epidemic in the next decade) and at the crossroads of international travel, there is a high probability of the HIV virus being brought in by foreign visitors and by the large number of Singaporeans visiting other countries. Internally, the new generations entering the age of sexual maturity as well as the adult population need to be constantly informed of effective measures individuals need to take and of the social policy measures that have been taken, including medical and counselling services available. The population needs also continuous encouragement to take HIV screening tests. And secondly, following the experiences of developed countries, more attention should be paid to foster local medical and social research on AIDS. AIDS research represents one of the most urgent challenges for biomedical scientists searching for a vaccine and a cure, and for social scientists investigating the problem of behaviour modification and other related issues.

NOTE

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