AIDS: THE SOCIAL DIMENSION

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INTRODUCTION

The AIDS epidemic may well become the greatest public health crisis of the twentieth century. There is widespread public recognition that it poses a fearful threat to the life and health of millions of people worldwide. There is also a recognition that the burden on our health-care system and on the national economy, already significant, is likely to increase dramatically. What is, perhaps, less widely appreciated is that our social responses to AIDS pose a serious threat to the shared attitudes and values that define us as a moral community.

If Canadians were invited to think about the total of accumulated capital in our society, most would likely take into account physical assets such as factories, mines, and office buildings, and the infra-structure of roads, railways, ports, and power grids. Only rarely would we think to include the complex of norms that makes possible and sustains all social activity. And yet these norms, which include respect for such values as rationality, altruism, public-spiritedness, and a sense of humanity, are no less essential to our social survival and human flourishing than are the sources of power that drive the economic engine. Some would say that they are, if anything, more essential.

Our social capital, not unlike our economic capital, can erode and dissipate if it is not properly maintained.² Perhaps we need to be reminded more frequently, by both cultural anthropologists and moral philosophers, that 'the normative order makes the factual order.' That is, there exists in every society a fundamental set of cultural values that serves as a kind of social cement, binding individuals together into some kind of coherent community. At the same time, these foundational values define societies and give to each society its particular character.

Several of the basic values of Canadian society are threatened by our response(s) to the AIDS epidemic.

THE PLAGUE MENTALITY

Blaming the Victim

As Susan Sontag explains,⁴ 'plague' is not simply a name for such frightening diseases as cholera, yellow fever, and typhoid. Derived from the Latin *plaga*, originally meaning stroke or wound, the word is now primarily used metaphorically. It signals a collective calamity, a great evil or scourge. In common parlance, not every epidemic qualifies as a plague, not even when the disease has a high mortality rate, as polio did and cancer does. It seems to be the case that in order to be counted as a plague, an epidemic must be conceptualized as possessing a moral dimension, something that is inflicted rather than merely endured, and that is deserved as a punishment for sin. As Father Paneloux comments, in Camus's novel *The Plague*:

Calamity has come on you, my brethren, and you deserved it ... the evildoer has good cause to tremble. For plague is the flail of God and the world His threshing-floor, and implacably He will thresh out his harvest until the wheat is separated from the chaff.⁵

In every plague, the general population looks for some group to which blame can be attributed. The Black Death, for example, was blamed on the Jews, who were thought to have poisoned the wells (even though they themselves drank from the same wells as their fellow citizens).

Nor was the potentiality of plague to poison social relations confined to the distant past. The nineteenth-century European epidemics of Asiatic cholera were blamed by the rich on the poor, for being dirty and unhygienic. Indeed, the ruling classes in plague-stricken cities such as Hamburg came to regard the poor and vulnerable classes of society with almost complete contempt and fear, to the point of denying their human status. It may not be too far-fetched to link this insidious process of dehumanization to the subsequent popularity of Nazism in Hamburg, where the genocidal program of sterilization and extermination proved more congenial than elsewhere in Germany.⁶

Although cholera was no respecter of social class, and drew its victims from the highest as well as the lowest strata of society, its inexorable spread was worst among those condemned to live in conditions of overcrowding, with no effective sewage disposal and insanitary waterways. Naturally enough, the poor predominated amongst its victims. It was obvious even at the time (e.g., to Dr Robert Koch, discoverer of the cholera bacillus) that the only sensible way of preventing 'the plague' was to improve living conditions for the poor, while introducing such measures as clean air and water. As Richard Evans demonstrates,' blaming the victims could only aggravate the public health crisis. Koch's sound advice was ignored until it was too late.

In every European country threatened by the nineteenth-century cholera epidemics, social conflicts and apprehensions were exacerbated. Whatever moral and political shortcomings existed in society were exposed mercilessly. British historian Asa Briggs makes the key point forcefully: the cholera plague was a 'profoundly social disease',⁸ giving rise to rumours, suspicions, and conflicts. (Although mortality rates were even higher for tuberculosis, typhoid, smallpox, and measles, none of these diseases seems to have produced the psychological effect of cholera, which killed with alarming rapidity.)⁹

Epidemic diseases become prime candidates for plague status when the putative carriers of the epidemic are viewed as aliens, or marginal members of society, as 'the other' – because they are foreigners, or poor, or darker-skinned than the 'general population', or of the wrong religion, or the wrong sexual orientation.¹⁰ Indeed, the very distinction, so easily and thoughtlessly accepted, between 'the general public', on the one hand, and risk groups, on the other, strongly reflects and reinforces the 'otherness' of those who are infected or infectious. Why do homosexuals not enjoy the same status – as charter members of the general public – that heterosexuals do? What begins as a seemingly inconsequential verbal point can unwittingly lead to increased willingness to support demands for their isolation or for their exclusion from ordinary legal rights and protections.

The AIDS epidemic fits most of the usual plague stereotypes, and well deserves the title 'God's gift to bigots'. It is believed to have originated in Africa, and to have spread from there to Haiti, North America, and then Europe. This hypothesis, whether or not it turns out ultimately to be correct, has great appeal to those who associate 'the dark continent' with sexual incontinence and primitive behaviour. In North America and Western Europe AIDS has spread most rapidly among the sub-culture of male homosexuals and intravenous drug users. An infectious disease whose primary means of transmission are 'deviant' sexual conduct and the use of illegal drugs is easily incorporated within the model of divine retribution for sin. The blame and opprobrium that are attached to both homosexuality and IV

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drug use (because of their association with sexual promiscuity and personal indulgence) produce in people who are not members of these 'risk groups' a feeling of moral smugness. The dangerous and deviant minorities are 'getting what they deserve'.

The tendency to identify some group(s) as scapegoats – the guilty ones who 'deserve' their fate but who threaten to spread their disease to the rest of us who are not deserving of such punishment – has, inevitably, a brutalizing effect upon society. It changes the hearts of men and women, weakening their human sympathies. It prevents many people from recognizing that the plague deeply concerns us all, not simply those stricken with the disease. In the words of Camus, describing the city of Oran after the onset of the plague, 'no longer were there individual destinies; only a collective destiny, made of plague and the emotions shared by all.''' It is a sad irony of history that the AIDS epidemic has occurred at just that time when, in Canadian society at least, homosexuality was beginning to gain acceptance as a statistical fact rather than as a moral blight. There is now a very real danger that the AIDS epidemic will produce a homophobic backlash.

The irrational propensity to search for some group(s) to scapegoat not only serves to undermine the sense we have of our common humanity, it also ensures that public health measures to contain 'the plague' cannot work effectively. In the case of AIDS, for example, if society stigmatizes and isolates those who have AIDS or who are seropositive for the HIV virus, there will be a strong disincentive to be tested for anyone who thinks that he or she may be at risk. The more punitive are society's attitudes towards those who test positive, the more will those individuals at risk avoid being tested. But if those 'at risk' refuse to be tested – going 'underground', if necessary – then society misses a vital opportunity to educate and counsel those who are infectious about the steps they should take to ensure that they do not infect others. There is thus a strong argument, based upon public health considerations, for avoiding strenuously the irrational temptation towards scapegoating and blaming the victim. Prudence and morality combine to support the same conclusion.

When the 'medical model' of disease is abandoned in favour of the 'moral model', there is a good likelihood that the results will be counter-productive and harmful in a variety of ways.

Xenophobia

We live in a world characterized by a high degree of international mobility. Interchange among people of different nationalities occurs in a number of different spheres: economic, cultural, and touristic. The xenophobia that typically characterizes the plague mentality often leads to hostility against immigrants and foreign visitors. This hostility may, in turn, result in the erection of barriers against foreign visitors. It may also promote intercommunal conflicts between 'the general community' and the community of immigrants. In the Soviet Union, for example, news reports have stressed that foreigners are the prime source of HIV infection. This perception may well have influenced the Soviet government to adopt a policy requiring general testing (for HIV infectivity) of all foreigners who will be in the country for over three months, including students, tourists, and journalists. Those who refuse to take the test are subject to explusion.¹² The US Public Health Services has issued regulations requiring that immigrants be tested outside the country for infection with HIV, but this requirement does not apply to tourists, students, or resident foreign businessmen.

By contrast, there does not yet appear to be much public support in Canada for the efforts of a few demagogues to stir up feelings of xenophobia. It would, however, be naïve to suppose that there is no constituency for such dangerous over-reactions. If/when the level of public anxiety about AIDS rises sharply, a large constituency for such policies could easily develop. In every society, including Canada, there is a reservoir of distrust, suspicion, and ignorance that offers a fertile breeding ground for public hostility. In order to diminish the danger of such over-reaction, public health officials will be required repeatedly to stress the fact that the unavoidable interconnectedness of the modern world renders all such isolationist efforts futile. This prudential appeal could be buttressed by a moral appeal focusing upon the common humanity shared by citizens of every nation. The image of country after country isolating itself and its people behind a series of new 'Berlin Walls' is as ugly as it is ludicrous.

Certainly, very few thoughtful Canadians are likely to support proposals that we should seal our borders tightly against all foreigners – not once they appreciate that this would mean forgoing the economic benefits of tourism, foreign trade, and international business, not to mention the hardship that this would impose upon separated families and friends. But there is a worrying possibility that certain ethnic and racial minorities within Canada – such as Africans or Caribbeans – could face increased prejudice and discrimination. The media are already suggesting that sex with 'people from overseas' is a risky behaviour. 'People from overseas' is a thinly veiled code phrase for Africans and Caribbeans. The view is subtly reinforced that if 'we' avoid intimate relations with 'them', we can avoid AIDS.¹³

As a more effective and humane alternative to the punitive approach to epidemic disease, one might hope that the policy of the Canadian government would be supportive of efforts towards increased international cooperation, in the field of medical research and also in other measures necessary to promote global public health.

Irrationality

Of all the values threatened by the plague mentality, critical rationality is in some ways the most important and the most vulnerable.

Rationality is, almost invariably, the first casualty of any 'plague'. Fear of

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the unknown and inability to tolerate uncertainty tend to generate what might be called 'apocalyptic thinking'. In modern Canada, no less than medieval Europe, many people opt for the simplistic explanations that are confidently propounded by demagogues in preference to the complex hypotheses that are tentatively advanced by epidemiologists and scientific researchers. Since scientific explanations must frequently be adjusted or abandoned when they run afoul of inconvenient facts, they can never achieve the certitude of pseudo-moralistic explanations, whose very invulnerability to refutation is what disqualifies them from the status of genuine science.

It is worth noting that even in the superstitious world of fourteenthcentury Europe, there was a minority, including some public health officials, who recognized the connection between environmental factors, such as rats, and the bubonic plague. As a result, there were some limited attempts at rat control. For most people, though, it was simply easier and more attractive to blame the plague on Anointers and Jews. Bigotry, superstition, and ignorance had an easy win over scientific rationality.

When one reads that suburban communities around Toronto declined to participate in that city's public-health program to combat AIDS (at the cost of a few dollars per resident) on the grounds that AIDS was largely an inner-city problem, one cannot help feeling a certain *déjà vu*. The irrational tendency to treat epidemic disease as 'someone else's problem' persists even when the disease reservoir is at the city gates, as it were.

Since not everyone recognizes that rationality is among the core values of Western culture, it is important that we remind ourselves just why any threat to the value of rationality represents, at the same time, a serious threat to the very survival of our culture.

The struggle of our species to win a living from nature has been a long and difficult one. Even now, only a small part of the world's population enjoys any sort of material comfort. Most are condemned to an existence marked by poverty and disease. Whatever doubts one may have about the science and technology of Western civilization, it is beyond argument that such progress as we have achieved has depended in an important way upon the development of critical thinking: the habit of mind that honestly and patiently collects evidence with which to test our beliefs. Progress in agriculture, transportation, communications, and health could have come about in no other way. If we have, to some limited extent, managed to transcend the ignorance and poverty of our forebears, it is because, in our culture, blind superstition has partly given way to a more rigorous ethics of belief. The ethos of critical rationality insists that we apportion the confidence we place in our beliefs to the evidence available. When there is good evidence against a proposition, it should be disbelieved. When there is no good evidence for or against a proposition, we ought to suspend belief.

Perhaps no philosopher has given a more eloquent defence of the importance of strict rationality in our belief system than the nineteenth-century

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British writer William Kingdon Clifford. Clifford's ethics of belief is nicely summarized in his declaration that 'it is wrong always, everywhere and for any one, to believe anything upon insufficient evidence'. Clifford argues that no real belief, however trifling it may seem, is ever truly insignificant, for

it prepares us to receive more of its like, confirms those which resembled it before, and weakens others; and so gradually it lays a stealthy train in our inmost thoughts, which may someday explode into overt action, and leave its stamp upon our character forever.¹⁴

Although the adoption of a smugly moralistic tone towards the sufferers from an epidemic, such as AIDS, may give pleasure to some people, the pleasure is epistemically 'stolen' and therefore morally condemnable. No one is entitled to believe that AIDS represents divine punishment for sin when the distribution of the disease is such that many 'sinners' go unpunished and many 'non-sinners' become ill and die. As an aside, one might marvel at the elaborate mental contortions that enable religious fundamentalists to explain away the fact that lesbians are the group least at risk for AIDS infection. Is there, perhaps, some as yet undiscovered divine significance in this phenomenon?

Our beliefs and our modes of thinking are not simply private matters. They are common property, an inheritance to be passed on to succeeding generations. We have no more stringent duty than to guard the rationality of our beliefs by ensuring that they are based upon adequate evidence. Belief that is given indiscriminately degrades the believers and endangers their fellows. Belief that is based upon carefully tested evidence, after fair and full enquiry, binds people together and strengthens the human community.¹⁵

In the context of Canadian responses to AIDS, it may be useful to consider some illustrative examples of irrational thinking, together with its demonstrably harmful consequences.

North American physicians have known for some time that the HIV virus is not casually transmissible. To mention just one of many recent studies, it has been reported in *The New England Journal of Medicine* that 'of the more than 30,000 cases of AIDS in the United States reported to the Centers for Disease Control by February 1987, none have [*sic*] occurred in family members of patients with AIDS, unless the members have had other recognized riskrelated behaviour.¹¹⁶ Although the majority of household contacts shared household facilities, including beds, toilets, bathing facilities, and kitchens, as well as items likely to be soiled by patients' saliva or body fluids (e.g., eating utensils, plates, drinking glasses, and towels), none of the studies could demonstrate even a single HIV infection among household members who did not have additional exposure to HIV infection through blood, sexual activity, or perinatal transmission.

Despite all this evidence, some physicians and nurses persist in masking and gloving up in order simply to converse with AIDS patients by their bedside.

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When challenged, these health-care workers sometimes acknowledge that their behaviour is irrational, but justify themselves with the claim that donning mask and gloves makes them feel psychologically more comfortable.

When one considers the wider implications of such behaviour, however, it may be seen as very damaging from a number of points of view. First, it represents an indignity towards patients with AIDS, further isolating and stigmatizing them. More than this, however, it sends an entirely inappropriate and dangerous message to the public. At the same time as community health officials offer reassurance to the public that there is no need to quarantine persons with AIDS, and no danger to anyone who works or studies alongside persons with AIDS, some physicians are signalling, by their behaviour, that they believe the HIV virus to be casually transmissible. The inconsistent behaviour of physicians (or other health-care workers) who 'say one thing and do another' illustrates how irrationality is not merely a personal foible to be indulged but an impermissible violation of the ethical injunction to do no harm.

Consider: a seventy-eight-year-old woman was recently refused admission by four different Nova Scotia nursing homes because she carried the AIDS virus. She had contracted the virus from a transfusion of contaminated blood during an operation in 1985. Although she had not shown symptoms of the disease and her immune system was stable, she required care in a nursing home because she was suffering from severe arthritis.

Consider: Reverend Charles Farnsworth, headmaster of the Grenville Christian School, in Brockville, Ontario, where a mandatory AIDS-testing policy has recently been introduced, declared that a positive AIDS test would lead to exclusion from the privately run school. He acknowledged that much of the fear about AIDS transmission may be rooted in ignorance, but insisted that 'people's fears must be respected'.

Consider: Volunteer firemen refused to respond to a call for help from a Roman Catholic monastery that cares for babies with AIDS. Two firemen from the nearby Annapolis Volunteer Fire Brigade refused to answer an emergency call for oxygen when one of the babies began choking. The infant died several days later.

Consider: In a survey carried out during the summer of 1988, it was revealed that 56 per cent of 1,500 Canadians surveyed believed that working alongside a fellow employee with AIDS would constitute a workplace hazard. They favoured compulsory testing of all prospective employees. Similar testing was not favoured for drug or alcohol addiction, despite a barrage of negative publicity about its harmful effects in the workplace.

Consider: The St James-Assiniboia School Division in Winnipeg has assured parents that it is safe to allow teachers or pupils with AIDS to continue in school, but it has spent thousands of dollars purchasing rubber gloves for teachers in case a child should have a bleeding nose or be cut in a playground accident. Consider: Large numbers of Canadian medical-school students are strongly advocating compulsory AIDS testing for all hospital patients. When reminded that a negative test is no guarantee that the patient is not infectious, and that hospital policy recommends that full precautions be taken during every risky medical procedure, students continue to insist adamantly upon the need for compulsory testing. Whatever may be the adverse consequences for patients, these students 'want to know'. Moreover, many declare that if they were to learn that a patient was HIV-positive, they would refuse treatment. Some would plan their internship and residency training so as to avoid institutions in high-risk areas. Their attitude does not change significantly when informed of the epidemiological data showing no greater risk of AIDS among health-care workers than among the rest of the population.

Each of these Canadian examples illustrates dramatically William Clifford's thesis that irrationality in seemingly insignificant matters can produce, directly or indirectly, gravely harmful consequences for one's fellow human beings. If the medical community is going to tell parents that it is safe to send their children to school alongside a schoolmate or teacher who is HIVpositive, and if they are going to tell workers that it is safe to work alongside a colleague who is HIV-positive, and if they are going to tell the public that it is safe to eat in restaurants where a chef or waiter is HIV-positive, then it will not do for doctors to behave as if they really believe that AIDS is casually transmissible. It may not be possible for any of us entirely to eradicate all irrational fears about AIDS transmission. It should be possible for all of us to resist acting on the basis of such fears.

De-socialization

Canadian society is often described by cultural commentators as 'individualistic'. Although this term is not used with precision, it is usually meant to suggest a constellation of values that includes emphasis on individual rights and liberties, self-fulfillment, privacy, independence, and personal autonomy." Individualism, in this sense, is a central norm of Canadian society. But whereas individualism is only one of the central norms of Canadian society, it is *the* defining ideal of American society.

American culture proudly affirms the worth of the single individual, unconstrained in body or in mind, entirely independent of his fellows.¹⁸ Much of American literature celebrates the worth of the totally liberated, atomistic individual (as in the writings of Emerson and Thoreau). Critics of American culture such as Daniel Callahan¹⁹ and Christopher Lasch²⁰ are concerned that an excessive preoccupation with self, at the expense of community, has led America into a 'tyranny of individualism' so great as to threaten that nation's cultural survival.

The sharp antinomy between the individual and the state, so often observed in American culture, is much softened in Canadian culture by the stress on such mediating group loyalties as regionalism (we are not simply

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Canadians, we are Maritimers or Westerners or Québécois) and ethnicity. Although it has become a cliché, our symbol of 'the cultural mosaic', by contrast with the American symbol of 'the melting pot', points to the existence of strong popular identification with sub-cultures and subcommunities of various sorts. Moreover, again in contradistinction to our southern neighbours, Canadians have been historically altogether more enthusiastic about the interventionist role of governments at all levels. The government is expected to speak powerfully on behalf of the interests of the broader community, for example, by using taxing powers to fund such community programs as medicare and public education.

There is reason to fear that what we are calling 'the plague mentality' could so affect the tenor of Canadian social life that we too could follow the Americans into a state of hyper-individualism. The present balance between the pursuit of self-interest, on the one hand, and public-spiritedness, on the other, could descend into the unbridled pursuit of self-interest. The danger is that our society could come more closely to resemble Hobbes's 'state of nature', in which the life of man was 'solitary, poor, nasty, brutish and short'. The process of de-socialization has already begun, and unless we are vigilant, it could accelerate.

Every society functions on a symbolical no less than on a practical level. The political life of a community is heavily dependent upon its symbolic life.²¹ Fear and suspicion of other people, any one of whom is potentially a carrier of the murderous HIV virus, could seriously erode our already frail bonds of compassion and trust. As Daniel Callahan explains, in hard times options are fewer, choices nastier. Blaming and denunciation become more congenial than forgiveness and therapy. If life is going poorly, someone obviously must be at fault. The warm, expansive self gives way to the harsh, competitive self; enemies abound, foreign and domestic. Incivility or even nastiness become the norm.²² The problem is, of course, that it is precisely during 'hard times' that a society most needs to invoke the values of altruism, public-spiritedness, and civility.

Camus perceptively describes the inevitable tension between the need for human solidarity and the fear of contagion created by the plague mentality:

people, . . . though they have an instinctive craving for human contacts, can't bring themselves to yield to it, because of the mistrust that keeps them apart. For it's common knowledge that you can't trust your neighbour; he may pass the disease to you without your knowing it, and take advantage of a moment of inadvertence on your part to infect you.²³

Once avoidance and exclusion become the norm, we have lost a vital community resource. The plague 'within each of us' is not the submicroscopic virus as much as it is an extreme alienation from our fellow human beings. Canada could become, if we are not careful, the kind of society in which

passersby ignore the needs of accident victums, for fear of contamination through contact with blood, a society in which even the most chaste and faithful harbour a dread of other people.

Some may find this an unduly pessimistic scenario; but there is considerable evidence from social scientists in support of the view that socially cooperative behaviour does decrease when bonds of trust are attenuated by negative feelings. For example, the psychologist Harvey Hornstein and his colleagues discovered,²⁴ in the midst of their 'wallet-returning' experiment, that on 4 June 1968, the day Robert F. Kennedy was murdered, not one of the wallets that they set out was returned. Since the rate of return prior to this event had been a fairly steady 40 per cent, one is led to infer that people's feelings about the moral community in which they live can have a significant influence on their behaviour. When people develop negative feelings about their fellows, they become less public-spirited.

More than a century ago, Alexis De Tocqueville observed, in *Democracy in America*, that unbridled competitive individualism was leading towards a dangerous social fragmentation. There is today, in the era of AIDS, a great relevance to his warnings against a social environment in which man is 'ceaselessly throw[n] back on himself, alone, and confined entirely in the solitude of his own heart'. In our understandable concern for the looming public health crisis, we must not overlook the concomitant threat to community values. Spiritual impoverishment could prove to be one of the worst consequences of the AIDS epidemic. To counteract this possibility should be among our highest priorities.

CONCLUSION

The conclusion to which the arguments of this chapter point is that the AIDS epidemic is as much a threat to our cultural values as it is to our lives, our health-care system, and our economy. The phrase 'plague mentality' encapsulates a series of attitudes and values: victim blaming, xenophobia, irrationality, and desocialization. There is still time to counteract, decisively, the plague mentality. The survival of our common humanity is at stake.

NOTES

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