The embodiment of inequality

AIDS as a social condition and the historical experience in South Africa

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The Thirteenth International AIDS Conference, which took place in Durban from 9 to 14 July 2000, was the first to be held in a city in the developing world. It showed that the international scientific and political communities are now ready to face the serious situation in developing countries, first and foremost those in Africa. And, as the title proclaimed, the conference sought to 'break the silence' surrounding such crucial issues as infection statistics and the social exclusion of patients, and also the lack of mobilization among rich nations on access to drug treatment. In this context, the choice of South Africa, which had only returned to democracy six years before from the apartheid regime, was highly symbolic.

However, as the event approached, the tension mounted among the medical world and advocacy groups. For several months, South Africa's President, Thabo Mbeki, had been open to the theories of some Western researchers who denied the causal relationship between viruses and infection. He had even invited some of them to a panel and had temporarily stopped all mother-to-child transmission prevention programmes on the grounds that the medication used was harmful (Schneider, 2002; Fassin, 2002a). In response to Mbeki's actions, some participants considered not attending the meeting, fearing that their presence would seem to condone this dissident assessment. The conference did finally take place, but Thabo Mbeki's opening speech was given to a half-empty auditorium after most participants had ostensively left.

The South African President declared that he had wondered long and hard about what could explain the virulence of the AIDS virus that was wiping out many more people in Africa than in the developed world: "As I listened to this tale of human woe, I heard the name recur with frightening frequency, Africa, Africa, Africa! As I listened and heard the whole story told about our country, it seemed to me that we could not blame everything on a single virus. The world's biggest killer and the greatest cause of ill health and suffering across the globe, including South Africa, is extreme poverty" (Mbeki, 2000; *The Lancet*, 2000). If the conference participants did not realize this, he added, that was because they knew nothing of the geography and history of the "African world of poverty", the world that he, Thabo Mbeki, was familiar with. This conclusion was obviously unacceptable for the scientific and activist communities because it gave precedence to socio-economic interpretation over biomedical explanation. It was precisely on the basis of this opposition that the most violent controversy yet about AIDS developed, with verbal clashes between two camps: one led by the South African President and brandishing the slogan "poverty causes AIDS"; the other including activists, physicians and political opponents, representing scientific authority under the banner of the "viral aetiology of AIDS". Thabo Mbeki was regularly branded as a "denialist" and was even accused of being responsible for "genocide", as he recalled in his opening speech at Durban. The purpose of this article is to get beyond this Manichaean vision and explain the epidemic in a way that takes into account both biomedical knowledge and socio-economic understanding. It is from this perspective, in an attempt to conceive how history becomes physical reality and how biological facts become social facts, that I use the expression 'embodiment of inequality'.

Hans Holbein the Younger (1497–1543) *Die Abtißinn* (The Abbess) from the *Bilder des Todes* (Pictures of Death) series; woodcut by Hans Lützelburger and Veit Specklin; 6.5 × 4.8 cm; with permission from Public Art Collection Basel, Switzerland.

The health disaster in Southern Africa started precisely at the time when long-awaited political changes were occurring in the whole region: the end of apartheid and the return of democracy to South Africa, independence for Namibia, and the conclusion of a series of wars, namely those in Mozambique and Angola. Southern Africa was spared the retroviral infection through the late 1980s; after that it became the world's epicentre (South African Department of Health, 2000; Whiteside & Sunter, 2000). In the early 1990s, the seroprevalence rate of HIV in the general population was less than 1%. Ten years later it was above 25%, and as high as 33% in the province of Kwa-Zulu Natal. Today, about 5 million people in South Africa are estimated to be infected with HIV. Demographers predict life expectancy will decrease by as much as from 60 to 40 years by 2010. From 1985 to 2000, the mortality rate doubled for men between 30 and 39 years old and more than tripled for women aged between 25 and 29. AIDS became the country's biggest cause of mortality, accounting for a quarter of deaths overall and half the deaths among people between 15 and 49 years old—young people are now dying in greater numbers

than the elderly (Dorrington *et al.*, 2001). South Africans themselves, particularly residents of the townships, have daily experience of the epidemic, and one need only look at the photos of young men and women that fill the obituary pages of the *Sowetan*, a newspaper with an essentially 'African' readership, to have an idea of the increasing ravages of AIDS.

In this context, talking about an epidemiological crisis does not merely indicate how rapidly the infection is progressing or how serious its manifestations are, but also how difficult it is to think about the reality of the epidemic and to talk about it. With the epidemic has come a crisis of discourse, first of all about the figures: HIV seroprevalence rates, mortality statistics, survey results, the choice of pregnant women as reference group and the value of HIV tests—all have been contested. Next, there is a crisis of interpretation, in which various behaviourist and cultural models are getting great attention. Sexual promiscuity is high on the list of explanations for unregulated behaviour: large numbers of partners and loss of norms among African populations. And as for cultural specificity, a presumed belief in purifying oneself through sex with virgins has lent a certain exoticism to the sad ordinary reality of the rape of young women and girls.

The crisis in discourse is closely tied to the crisis caused by the epidemic itself. What is often too readily called 'denial' is actually an inability to make sense of the overwhelming experience of AIDS. There are two distinguishable forms of such a reaction (Cottereau, 1999). One is the denial of reality, the temptation to say, "This cannot be, this is not possible". The other is justice denied: "This should not be, this is not fair". These two operate together in denying the harsh facts of the AIDS epidemic. It is indeed impossible to grasp the reality of a disease that dooms one adult in four, which could well make Africans a minority in South Africa within a short time, as stated by the director of the country's Medical Research Council. Such a phenomenon is incomprehensible, not only for the residents of a township, but also to health ministry administrators and even, to some degree, to demographers and epidemiologists. It is unbearable that such misfortune should fall on South Africa at precisely the moment that it is discovering civil rights for all; it is unacceptable that Africans, who have repeatedly been the victims during their country's history, should once again have to pay the highest toll; and, finally, it is inconceivable that the country's first democratic government should be accused of genocide, whereas this term was never used against the Whites when they were in power.

Hans Holbein the Younger (1497–1543) *Der Münch* (The Monk) from the *Bilder des Todes* (Pictures of Death) series; woodcut by Hans Lützelburger and Veit Specklin; 6.5 × 4.8 cm; with permission from Public Art Collection Basel, Switzerland.

To account for both the crisis in reality and the crisis in discourse, the violence of the epidemic and the violence of the epidemiological truth, it is perhaps necessary to read the situation differently and put the question thus: how can we explain why AIDS has so quickly and so deeply shaken South African society (Marks, 2002)? First, I will examine the logic behind the hard fact of the unequal distribution of AIDS morbidity and mortality in South African society. Just as poverty is not a necessary and sufficient cause for tuberculosis (TB), but rather is what epidemiologists call a 'risk factor', there is a similar link for AIDS between social reality and biological facts: what anthropologists call a 'structural condition' for the development of the epidemic. Second, the disease clearly does not just involve a pathological process that attacks the physical body, but also reveals a historical truth that exercises the social body. What patients recount and what politicians debate, the narratives of the first and the denial of the second, all the qualification, interpretation and justification, also arise from the embodiment of inequality.

My point in speaking of the 'social' rather than 'human condition', is to assert that humans live within a social order characterized by hierarchies and inequalities (Fassin, 2001). And AIDS is a social condition in the sense that it not only unites human beings in common suffering, it also divides them in terms of exposure to risk and access to treatment, their ability to confront the problem, and their chance to die with dignity. The distribution of wealth, the status of women, health and social policies, the activism of advocacy groups and professionals—all are factors leading to disparity among individuals. When Mbeki spoke of 'poverty' as the biggest cause of death in Africa, he more precisely meant 'inequality'. In South Africa, three features of inequality seem to be particularly important: the socioeconomic situation, violence and migration. These in turn can be understood only in the light of the country's history.

The socioeconomic situation is a determining factor in the distribution of the disease (Farmer, 1999). In the 1980s, when the virus had just begun to spread in South Africa, it affected mainly white, affluent, urban homosexuals. However, it quickly became clear that inhabitants of the townships and homelands—the spaces to which Blacks were confined—were in fact paying the higher price of the disease. The most recent epidemiological studies illustrate two lines of differentiation: an inverse relationship between seroprevalence and skill level, which is independent of ethnicity, and much higher infection rates for Blacks than Whites with the same occupation (Johnson & Budlender, 2002). Combining these two

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factors results in a tenfold higher probability of infection among unskilled black workers than among white management. More generally, estimates based on surveys of pregnant women show that Africans are sixfold and eightfold more likely to be contaminated than Coloureds and Whites, respectively. In post-apartheid South Africa, these socio-economic inequalities are inscribed in racial distinctions that were constructed during several centuries of exploitation, domination and segregation. They are reflected in the material conditions that influence the risk of contamination: lack of financial resources, which puts young women at the mercy of the sexual demands of men; unsafe neighbourhoods, which increases the risk of rape; mothers working far from home and leaving their children alone. Furthermore, low investment in black education results in less knowledge about how the disease is transmitted, how it can be prevented and about individual rights.

Sexual violence is the second structural feature of the AIDS epidemic in South Africa, as in many other places throughout the world (Wood *et al.*, 1998). Of 477 rape victims received and cared for at the Greater Nelspruit Rape Intervention Project, 285—three out of five—were under 15 years old, and 45—one in ten—were under 5 years old. And this is only a low estimate, as the vast majority of raped women and children do not even have access to such projects and never show up in the statistics. The public representation of the problem, reinforced by references to supposedly traditional beliefs in the purifying virtues of raping young girls, has made sexual violence seem a distant, literally extraordinary reality. By contrast, surveys of, and testimonies from, victims attest to the ordinariness of rape, and, more generally, 'unwanted sex under constraint', including between regular partners and married couples (Robertson, 1998; Jewkes *et al.*, 2003). Although historical studies attest to the existence of pre-colonial tribal violence, there is no doubt that the colonisation of Africa brought further radicalization of social violence. First came the colonizers' direct violence, followed by the apartheid government's violence against Blacks—everyone knows with what brutality racial order was imposed and protest movements repressed. Second was the violence induced by the white authority's non-engagement in the townships and homelands that were to a large degree abandoned to local, sometimes corrupt, black authorities. This twofold strategy—excessive power, and power exercised by default—made illegitimate violence the ordinary substance of social relations, compounded by easy access to alcohol. Most African adults grew up knowing no other form of social relations than these forms of violence, either from the state or in their own community.

Hans Holbein the Younger (1497–1543) *Der Graff* (The Earl) from the *Bilder des Todes* (Pictures of Death) series; woodcut by Hans Lützelburger and Veit Specklin; 6.5 × 4.8 cm; with permission from Public Art Collection Basel, Switzerland.

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Migration is a well-known risk factor for infectious diseases, especially sexually transmitted ones (Web, 1998). The term migration is misleading, however, in that it suggests a relatively homogeneous phenomenon. Movements of individuals and groups can, in fact, have sharply different meanings, and it is precisely this complexity that must be taken into account if we are to understand such movements. The first migration between urban and rural environments was due to insufficient agricultural resources and the demand for industrial and domestic labour. It has increased since the end of apartheid, which also saw the end of the humiliating passes used to keep persons without work permits inside townships or homelands. Such migration rapidly became a major public health concern, with men leaving behind their wives and children, starting second and even third families near their workplaces, and then going home to contaminate their wives. In fact, recent epidemiological studies of serodiscordant couples in rural KwaZulu-Natal showed that in 40% of cases it is the woman who is infected, a statistic that, together with the miserable living conditions in hostels and shacks, suggests that the question of the respective roles of the two sexes in transmitting the disease should be reconsidered (Lurie, 2000; Williams *et al.*, 2002). In addition to this internal migration, there were four border-crossing dynamics. First were populations fleeing war and repression from Angola, Rwanda, Burundi and Congo, who settled sometimes in camps, but mostly on city outskirts. Second were veterans of the South African National Defence Corps, soldiers who were withdrawn from their bases in Namibia and Mozambique, and moved into special military settlements. Third were members of the long-banned African National Congress and South African Communist Party, who returned to their land after exile. Last were Central and West Africans, and others from impoverished neighbouring countries, migrating to what they saw as a new Eldorado—democratic South Africa.

For the individual, socioeconomic difficulties, violence and migration are often interwoven into a sad reality. What is sometimes called 'survival sex' means that young girls from poor rural areas with no economic resources other than their bodies going to bars where drunkenness has reduced inhibitions and having sexual relations with men they have just met in exchange for money, food, sometimes shelter and even a bit of warmth (Wojcicki, 2002). But, once again, this image of multiple sexual

partners, which is too readily generalized, is both dangerous and unfounded: dangerous because it is precisely by means of stereotypes focused on sexual promiscuity that Africans have been stigmatized and, in reaction, have developed resistance to 'racist' AIDS prevention campaigns; unfounded because epidemiological data have established that high rates of infection are not correlated with unusual sexual behaviours—in some mining towns, HIV seroprevalence is 50% among women from neighbouring townships who have had three partners in their lives, 35% among women who have had two partners, and still 22% among women who have had only one (Williams *et al.*, 2000). Although having multiple sexual partners is an aggravating factor, it cannot stand as the sole explanation of the epidemic's explosion (Buvé *et al.*, 2001; Gisselquist *et al.*, 2002).

To interpret these terrible figures, we need to approach health in terms of political economy. Since the late nineteenth century, when gold and diamonds were discovered in South Africa, the mining industry has taken increasingly large labour forces from African villages. The cost of the industry's violent exploitation of the native Africans in terms of human lives and diseases has been high, and large numbers of miners have died from TB and silicosis (Packard, 1992; Katz, 1994). This exploitation was facilitated by a form of social organization conceived entirely to benefit mining interests. Men were confined to barracks and hostels set up at the mines. Meanwhile, the companies made alcohol and sex readily available—a reality that justifies speaking of institutionalized risk. Seroprevalence rates are thus understandably grim: in Carletonville, near Johannesburg, they are 29% among miners, 37% among women living in the township and 69% for prostitutes living on the mining grounds. Clearly, the behavioural and cultural explanations commonly cited to account for the epidemiological reality fail; what makes that reality comprehensible are the economic structures and political processes that constitute the country's history (Campbell & Williams, 1999).

For Reinhardt Koselleck, history is first and foremost the product of experience, whether individual or collective: it is the experience transmitted from generation to generation (Koselleck, 1997). He goes as far as to affirm that "history is always made in the short term by the winners who, though they may prolong their victory over the medium term, can in no case dominate over the long term". On the contrary, losers' narratives are heuristic because "it all happened differently from what they expected or hoped". Historical experience is thus not only intellectual: it is a profoundly bodily experience, in the form of never-healed wounds and ever-present reality (Fassin, 2002b). The social experience of AIDS is therefore made up of both individual biographies and collective narratives. It is the way in which persons with AIDS pore over their pasts in search of misdeeds. It is also the way in which the government, relayed by large segments of public opinion, alternately accuses political opponents, AIDS activists, multinational pharmaceutical companies, and Whites and Westerners for incriminating the young democracy or attempting to reduce the black population. In short, there is experience of guilt and of suspicion. These two interpretations of AIDS are not the only ones, but it is clear that guilt and suspicion founded in South Africa's history dominate the experience of the disease.

Hans Holbein the Younger (1497–1543) *Daß jung kint* (The Young Child) from the *Bilder des Todes* (Pictures of Death) series; woodcut by Hans Lützelburger and Veit Specklin; 6.5 × 4.8 cm; with permission from Public Art Collection Basel, Switzerland.

The experience of guilt recalls the long history of missionary work in the country, which was more effective than the military conquest in facilitating ideological control of the colonized (Comaroff & Comaroff, 1991). It has effectively promoted a sense of individual responsibility for each person's own fate and a sense of supposedly deviant behaviours. This process is closely linked to a normative system in which doctors have had a particular role and disease has often served as a justification to impose moral values, notably for syphilis (Butchart, 1998). The spread of this sexually transmitted infection in the early twentieth century was interpreted as the consequence of Africans' 'amoral' conduct, especially women, who were readily labelled 'prostitutes', and expressions such as 'promiscuous sexual intercourse' were already being used at that time. With AIDS, the same stereotypes reappeared. This racial profiling is not just a representation of the social world but also of the institutions established to administer it in the areas of education and health prejudices (Packard & Epstein, 1992). Once again, Africans found themselves in the position of the accused, according to a principle that has long been used in public health: the principle of 'blaming the victim'.

The experience of suspicion has even stronger roots in South African history than that of guilt. In the early 1980s, rumours began to spread in Eastern Europe, Latin America and sub-Saharan Africa that AIDS was a plot—in most variations, a plot hatched in the USA—to be used against Third World countries. But nowhere has this suspicion been more continuously expressed in the media and more vehemently relayed by the political forces than in South Africa. Statements that the virus was introduced deliberately into the continent, that heterodox theses were being censored, that antiretroviral drugs could prove dangerous to Blacks and that public health programmes served to disqualify African societies found receptive listeners in South Africa. But if we examine these affirmations closely, we see that they too contain truth, not about the disease as such but about the social world (Schneider & Fassin, 2002).

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The history of public health in South Africa is closely tied to racial domination. The first segregation measures were introduced during a plague epidemic in 1900 in Cape Town (Swanson, 1977). Justifying their action on the basis of the Public Health Act of 1897, the authorities decided to expel the African inhabitants of the city and resettle them in so-called 'native locations'. If we consider that few Africans were actually infected at the time, this measure was more reflective of prejudices about the health risks posed by these people's miserable living conditions than of any direct or immediate danger. Public health was used as an argument to clear the city of its black neighbourhoods. A few years later, between 1910 and 1935, another infectious disease, TB, came to the aid of the mining industry (Packard, 1990). The spectacular spread of this disease among African workers was accounted for by a supposed inherited susceptibility rather than by the actual working and living conditions. The idea that regularly renewing the labour force would reduce the spread of TB was used to justify repeated transfers of black workers back and forth between rural zones and mining regions, thus speeding the spread of the disease. In the late 1980s and early 1990s, the Africans' peril became actual again with AIDS, with certain conservative officials openly rejoicing at the prospect that the virus might eradicate the black population (Van der Vliet, 2001). With discourse radicalized to such a point, the degree and depth of suspicion within the black population is hardly surprising.

But those convinced that AIDS is a plot to destroy Africans have found other confirmation of their suspicions, namely the discovery of the warfare machine that the apartheid government created. It was only in 1998, after testimonies by internal security service officials, that the Truth and Reconciliation Commission decided to open a Chemical and Biological Warfare file (Truth and Reconciliation Commission, 1998). They found that the chemical and biological weapons programme aimed not only at eliminating political enemies but also at eradicating the African population as a whole, particularly by sterilizing women without their knowledge. During the trial of the programme's scientific director, Dr Wouter Basson, South Africans learned that HIV was among the infectious agents that these officials considered using in their genocidal plan. Experiments included sending contaminated veterans to hotels in poor neighbourhoods so as to infect Blacks through local prostitutes (De Lange, 2000; Sapa, 2000; Hogan, 2000; Gould & Folb, 2000). What had seemed to be pure fantasy turned out to have been ghastly reality, even as a partly aborted project. In view of these facts, people's suspicion of science and medicine, seen as instruments of white domination, takes on a tragic dimension. In surveys I conducted in the townships, respondents constantly referred to the secret programme and its director—commonly known as 'Dr Death'—when expressing doubt about affirmations made to them about AIDS.

President Mbeki's opening speech at the Durban Conference set his social interpretation of AIDS against the biomedical model, and the media have unremittingly demanded that he state whether or not he believes that the virus causes the disease. Meanwhile, no one has explored an alternative interpretation of Africa's AIDS epidemic in which social and biomedical theses are compatible. It is such an interpretation of the disease that enables us to hear the two truths contained in Mbeki's speech. The first is that biological and behavioural explanations cannot provide an exhaustive interpretation of the epidemic; observable inequalities must have a place in the aetiological model of AIDS. The second is that dominated peoples' view of their own history must be heard; experienced inequality is also part of the global reality of AIDS.

It is of course regrettable that these important truths have been buried under ambiguous dissident theses. But it is also surprising that so few medical and social science researchers have tried to untangle orthodox and heterodox interpretations. In speaking here of the embodiment of inequality, in seeking to give a hearing to the material and social truth of AIDS in South Africa, I have tried to weave together a general interpretation of the AIDS epidemic. The terrible afflictions of our time are not exclusively natural disasters. They speak to us of the order and memory of our societies.

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