Anthropologies of Modernity
Foucault, Governmentality, and Life Politics

Edited by Jonathan Xavier Inda
The second image is that of the West’s most celebrated political icon: Thomas Hobbes’s Leviathan. I want to note that in the image that introduces the text the city is emptied of people, with the exception of a few soldiers, and the population is present in the figure of the sovereign — their faces are actually inscribed in its figure — which rules in a ghost-like manner outside the city walls. Here power has to do with transforming people into a population embodied by the sovereign. The citizen is absent from the city and bodiless, one could say. So, how are people made into absent things?

The dying city reappears in Foucault’s Discipline and Punish: The measures brought into seventeenth-century European plague-ridden cities were a kind of precursor to the automatic functionings of power that Foucault exemplified in Bentham’s panoptic model. “The registration of the pathological must be constantly centralized. The relation of each individual to his disease and to his death passes through the representatives of power, the registration they make of it, the decision they take on it” (1979: 197). In the eighteenth and nineteenth centuries, individual bodily discipline was increasingly combined with the regulation of the biological processes of populations, leading to emergence of what Foucault calls biopower: “If the old right of sovereignty consisted in killing or letting live, the new right will consist of making live and letting die…. The new right will not cancel the first, but will penetrate it, traverse it, change it” (1992: 172). Biopower is a “scientific power” which works continuously, changing scales, areas of action, and instruments of government. Government is no longer based only in the visible body but on living man as part of the species: “a new body emerges… a multiple body, with a numerous if not infinite quantity of heads. Biopolitics works with the notion of population… population as a biological problem, and as a problem of power” (1992: 176; see also Foucault 1991). Modern politics is increasingly played out in the physiology of the citizen: “modern man is an animal whose politics places his existence as a living being in question” (1980: 143). The question remains: Life for whom? Who is to be let die?

In this essay, I reflect on a new and emergent biopolitical paradigm: the Brazilian control of AIDS, which combines prevention with free distribution of antiretroviral therapies and is widely touted as a model for stemming the AIDS crisis in the developing world. Strands of these various political elements I alluded to are recombinant in this policy, which came into existence through an assemblage of international financial institutions, commercial science, a re-forming state, and nongovernmental mobilization — all in a context of deeply entrenched inequality. In the face of the devastation brought about by AIDS, the unlikely availability of a vaccine in the near future, and the relatively few interventions that seem replicable, this is a most welcome success story. It emerges not out of utopian principles or privileged contexts but from being near to desperate realities and redirecting seemingly inflexible commercial scientific and state logics toward equitable outcomes. After briefly historicizing the development of this novel form of biogovernmentality, I will examine concrete situations in which the AIDS policy...
is involved and the ways in which it affects local trajectories of the epidemic both institutionally and in lived experience, particularly in urban poor contexts where AIDS is spreading most rapidly. From the perspective of the marginal and poor people with AIDS living in the streets and in and out of pastoral institutions, we see that economic globalization, state and medical reform, and the acceleration of claims over human rights and citizenship coincide with a continuous local production of social death that remains by and large unaccounted for.

The AIDS Model

State, civil society, and market restructuring play an essential role in any understanding of the Brazilian AIDS model. In 1992 the World Bank and the Brazilian government approved an unprecedented 250 million dollars aid package for the creation of a National AIDS Program whose aim was to reverse what international experts were calling the “africanization” of AIDS in Brazil (Lito É/Sembrer 1991: 52, Biehl 1999; Galvão 2000). AIDS activists, politicians, economists, and scientists organized an impressive governmental and nongovernmental administrative apparatus that is believed to have contained the epidemic’s growth through massive and community-mediated prevention projects, with a particular focus on condom distribution, HIV testing, and behavioral change among the so-called high-risk groups (Coordenação Nacional de DST e AIDS 2000). In 1996 national data began to show a decrease in the epidemic’s rate of growth. The National AIDS Program and the World Bank agree that half of the projected 1.2 million HIV cases have been averted. In November 1996, President Fernando Henrique Cardoso signed a law that made anti-HIV drugs available to all registered AIDS cases. In the words of epidemiologist Pedro Cherquer, former National AIDS Coordinator and designer and implementer of this management: “This drug policy increased self-reporting and, as a result, we have achieved near universal registration” (personal communication, 2000). Approximately 135,000 patients are taking AIDS therapies today. The availability of the cocktail and laboratory testing, funded by the Brazilian government at an annual cost of 2,000 dollars per patient, has reduced the use of hospital services and AIDS mortality by more than 50 percent in São Paulo and Rio de Janeiro, the most affected areas of the country. Mother-to-child HIV transmission has been reduced by two-thirds.

As the Brazilian state renegotiates contracts with multinationals and threatens to overturn international patent laws in the name of protecting public health, this innovative program is also strengthening the country’s scientific infrastructure and pharmaceutical industry. As Dr. Elza Pinheiro, the former director of Far Mantinos, the state’s main pharmaceutical company that produces many of the generic antiretrovirals that are being consumed, explains: “We have reverse engineered two drugs that are under patent protection and we are ready to go into production if the government deems it necessary. The multinationals must become flexible, and we must all deal with the question of whether new technologies are going to benefit man or exclude him from the possibility of surviving” (personal communication, 2001). As to her way of doing science, Dr. Pinheiro does not agree that it is sheer copying: “We had to develop our own methods of analyzing the drugs. I traveled to China and India to learn and to buy salts from them…. Sometimes, if we want the species to survive, we have to regress from some advanced logics that are in place” (personal communication, 2001). Here, out of constraint and imagination, global market logics and the politics of science and technology are forced into explicitness and become a new and productive field of tension and negotiation.

This policy of biotechnology for the people is being hailed as “proof that poor nations can do it” and as “a model for treating AIDS worldwide” (Rosenberg 2001), and the Brazil story is now an important component of international medical activism (e.g., Doctors Without Borders, Oxfam, and Partners in Health). The Brazilian response to AIDS challenges the perception that it is impossible economically to even consider intervening in the pandemic’s course in low-income countries, and calls our attention to the possible ways in which biotechnology can be integrated in public policy and can contribute to political and human advancement in developing contexts, even in the absence of an optimal health infrastructure. Affirming the need to combine prevention policies with treatment, this policy opens a political and moral debate on the role of industry, medical science, government, and philanthropy in providing medications to poor countries, and of the immediate and long-term implications of doing so.

From 1992 to 1997, and 1998 to 2001, I carried out fieldwork in state, corporate, scientific, nongovernmental and local public health institutions, whose restructuring went hand in hand with what I call the Brazilian “AIDS transition.” I also worked in community-run services and with marginal populations living with AIDS in the streets and without access to care in southern Porto Alegre and in northeastern Salvador. In my longitudinal ethnographic work, I charted the technical and political means through which such an innovative public health intervention has been engineered at a state marked by corruption, arbitrariness of resource allocation, inefficiency, and general inattention to abysmal social and health inequality. I am particularly interested in the ways in which populations are medically and bureaucratically restructured around this unique access to life-extending treatments.

My research concerns are situated in the fields of medical anthropology, science and technology studies, development, and international health. In the early 1990s, anthropologists began to closely follow the production of new bioscientific knowledge and the making of biotechnologies, inquiring into their multiple deployments and into their interactions with old and new forms of power relations (Strathern 1992; Rabinow 1996, 1999; Rapp 1999; Lock 2002; Fischer 2003). Rabinow (chapter 7, this volume), for example, notes a dissolution of the
traditional social domain and the emergence of new forms of identity and moral reasoning around the technical possibility of the literal remodeling of life (what he calls “biosociality”). Medical anthropology has come a long way from its initial emphasis on ethnomedicine, which focused on folk categories of sickness and healing and countered them with Western biomedical diagnostics and treatment. The recent work of anthropologists Veena Das (1995, 1999), Arthur Kleinman (1999), and Nancy Scheper-Hughes (2000), to mention a few, show how medical and technical interventions affect—sometimes for better, sometimes for worse—the etiology, experience, and course of disease. The appearance and distribution of disorders such as drug-resistant tuberculosis and AIDS are also closely correlated with poverty and social and technological inequality. They are “pathologies of power” (Farmer 1999, 2003) mediated by biological, social, and technical and political-economic mechanisms. Concrete biological phenomena are intertwined with environmental conditions that are part of a grander human life context, and it is in this complicated web that the individual’s illness experience is constituted.

Most social scientific accounts explain the Brazilian “antiretroviral revolution” in terms of the strength of social mobilization in Brazil. Gay activist groups and AIDS activists and experts working at the level of national and international mobilization and lawmaking played a great role in forcing the state to fulfill its constitutionally mandated health obligations (Galvão 2002). What remains largely unconsidered are other political and market forces that have been determinant to the AIDS policy’s current form and course and which I briefly address in this essay. The main focus of the essay, however, is on the new fields of exchange and possibility that are generated as state actors and institutions reach out and so-called marginals leave (some successfully, some not) their predetermined place and face AIDS and its technical and political apparatuses. What social capacities and institutions are instantiated? What destinies do marginals living in complex urban settings embrace as they are slated for intervention? More broadly, how are disease, misery, and marginality governed through the AIDS response? Throughout, I argue that selective life extension and social death are the two poles of a continuum through which the state, medicine, community, and the citizen empirically forge and modulate their existence today.

AIDS and Democratization

AIDS emerged in Brazil in the early 1980s, concurrently with the demise of a military state. Its growth coincided with the country’s democratization amid a ruined economic and social welfare system (Parker and Daniel 1991; Parker et al. 1994; Galvão 2000). First reports showed that AIDS was most prevalent in urban centers, among men who had sex with men—but this epidemiological profile would rapidly and dramatically change (Bastos and Barcellos 1995, 1996). In 1985, 79 percent of the reported AIDS cases were individuals who had either finished high school or had a college education. Ten years later, 78 percent of the reported AIDS cases were illiterate or had only finished elementary school. In 1983, there were 40 men for 1 woman with AIDS; in 1990 the ratio was 6:1. In 1996 the ratio was already 3:1, and now it is almost 1:1. Amid panic, fear, and discrimination, the government’s refusal to seriously address AIDS and its systematic nonintervention would play a determinant role in the unfettered course of the epidemic in the country (Scheper-Hughes 1994).

In those early years of AIDS and in the absence of international and national support, the response to the epidemic sprang from grassroots movements, most notably from gay activists who pressured local municipal and regional health services for information and treatment, and carried out prevention campaigns. In São Paulo, for example, such a mobilization led to the creation in 1983 of a state-wide public health AIDS Program, the first of this kind in Latin America (under the supervision of Dr. Paulo Teixeira who would later bring this knowledge to the National Program). Here grassroots and regional state interventions were not antithetical to each other. They had in common a progressive political commitment and understood the need to integrate information and care and pragmatically established alliances with health technicians and philanthropic institutions (Teixeira 1997). The AIDS epidemic also occasioned the creation of several new nongovernmental organizations throughout the country. These new social movements galvanized demands and actions aimed at securing citizenship and human rights mandated by the new progressive constitution of 1988 which made health everyone’s right and the state’s duty. This universal right would have to find ways to be realized amid the country’s wholesale neoliberalization and state dismantling. AIDS activists representing socially vulnerable groups such as homosexuals and sex-workers developed a strong public voice in the dispute over access to ever scarcer public and medical resources. While the underfunded and understaffed state public health services were increasingly paralyzed in their capacity to address the growing complexities of AIDS, grassroots spaces of health care emerged and bore the medical and social burden of the AIDS crisis among the poorest.

In the 1990s, with AIDS increasingly viewed as a development problem and with World Bank funds available, activists became less antagonistic toward the state and became key advisors to the National AIDS Program. The role of NGOs was central to the new forms of governmentality sought by sociologist President Fernando Henrique Cardoso (1998). Activists along with managers and scientists constituted a new “epistemic community” within the state (Rosário Costa 1996). This community sought to produce a transparent and efficient system of coordination between international monitoring and regional demands for intervention. The Brazilian AIDS epidemic also served as a test case for the World Bank’s development policies that called for institutional changes and a decentralized administration of well-targeted health-related projects for specified populations (World Bank 1993; see also Stiglitz 2002). The majority of funds were allocated
to AIDS prevention, mostly through NGOs (which grew from 129 in 1993 to 480 in 1999) and to the institutional development of regional and municipal AIDS programs. On the one side, these technically constructed and culturally sensitive prevention programs helped to create a new state credibility and a public discourse on sexuality and risk; on the other side, they failed to be integrated in the country’s precarious universal health care system. As the policy was being implemented, epidemiologists, demographers, and statisticians working within the Program and local health systems began to make the massive human scope of the epidemic legible.

By 1996, these interventions were said to be decreasing the epidemic’s rate of growth. At this moment in the AIDS policy’s course, we have afflicted populations represented by NGOs within the state and, at a local level, NGOs ruled by what anthropologist Jane Galvão calls “the dictatorship of projects” (2000). Also at local levels, we have religious and philanthropic organizations traying AIDS patients’ access to welfare and medical goods, a phenomenon I call the “pastoralization of the social domain” (Beihl 1999). Paradoxically, by 1996, a World Bank-funded infrastructure that was initially guided by principles of decentralization and prevention rather than direct assistance created the conditions for the democratization of access to the new resources of AIDS science. Widespread access to anti-HIV drugs—which we could also call “a technological surprise” (Aron 1951) redirected personal and political history and opened new markets. Indeed, as Sjaak van der Geest, Susan Reynolds Whyte, and Anita Hardon (1996) have pointed out, pharmaceuticals have a social life: they are part of booming economies and of novel political and symbolic actions.

I want to make the point that the developments around the AIDS policy dovetailed with former President Cardoso’s efforts to internationalize Brazil’s market. Not by chance, just a few months before the 1996 antiretroviral law was approved and succumbing to industry lobbying pressure, Brazil legalized patent protection for pharmaceuticals. Brazil signed the treaty on Trade-Related Aspects of Intellectual Property Rights (TRIPS) in 1995, and since the government was eager to attract new investments it allowed for immediate patent protection whereas other countries such as India and Argentina had until 2005 to conform to TRIPS. The Brazilian action led to a dramatic increase in the import of pharmaceutical products, making Brazil the largest pharmaceutical market in Latin America (and eighth largest in the world—see Bermudez 1995; Bermudez et al. 2000). It also led to a new form of leveraging power with big pharma. Pharmaceutical companies had already recouped their research investment on AIDS drugs, and with Brazil they enjoyed a new fixed market and unforeseen returns even in the face of lowered drug prices. Thus the Brazilian AIDS model has also become a model of developing new markets elsewhere. A pharmacoeconomic report on emergent HIV/AIDS pharmaceutical markets, namely Brazil, Thailand, India, China, and South Africa, argues that even if these governments provided the simplest version of the cocktail to some 30 percent of the affected populations at 10 percent of the current US price, in 2004 the industry would still make some additional 11.2 billion dollars.

Through the AIDS policy, one sees that economic globalization does not necessarily limit states. Rather, it opens up new prospects for states, and allows states to experiment with new forms of regulating markets for life-saving treatments. Grassroots activities as well those of public opinion combined to maximize social equity in the face of the market’s “inevitable” agency in resource allocation or denial. The work of nongovernmental organizations and their international counterparts gave voice to specific mobilized communities and helped to consolidate actions that were wider and more efficacious than state action alone. Empowered by the National AIDS Program, activists successfully forced the government to draft two additional legal articles that would allow compulsory licensing of patented drugs in a public health crisis, and this legislation created a venue for state activism vis-à-vis the pharmaceutical industry.

Internationally, the AIDS policy has also acquired a very powerful demonstrative power. Inspired on the Brazilian model, anthropologist-physicians Paul Farmer and Jim Kim and their Harvard-based organization Partners in Health have built up a pilot antiretroviral treatment project in impoverished Haiti (Farmer et al. 2001). They are now engaged with big Pharma representatives and philanthropic institutions such as the Gates Foundation in thinking the costs and possibilities of such projects in large scale for the developing world. Jim Kim is now collaborating with Dr. Paulo Teixeira, the former coordinator of Brazil’s AIDS Program at the World Health Organization, in among other things a project to bring AIDS therapies to at least 3 million people living in the poorest regions of the world by 2005.

Beyond such demonstrative power, however, I am concerned with how the AIDS policy coexists with historically entrenched mechanisms of social exclusion that continue to shape the course of life and death for Brazil’s most vulnerable. As the lives of many poor AIDS patients are being extended and the international pharmaceutical contract and ethics are being rewritten, my ethnographic work in northeastern Brazil shows that a large number of poor and marginal AIDS victims are absent from epidemiological statistics and health care and, with no apparent rights, are allowed to die in abandonment. These persons live in the streets or abandoned buildings, before the eyes of the public. In their troubled existence with AIDS, they have sporadic contact with governmental services of testing and medical care or with nongovernmental forms of support, but no specific programs of prevention and treatment support them. Their experience of dying is simply ordinary and met with political and moral indifference. The invisibilization of death among the poorest with AIDS is concomitant with the successful control of mortality as articulated by Brazil’s new biopolitical paradigm.
Science and Scarcity

These realities are neither the outcome of a simple progression nor are they absolutely new. So, before presenting some epidemiological and ethnographic data, let me briefly put these initial insights and arguments into historical perspective. Drawing from the past makes the present more comprehensible, and also illuminates how the current pharmaceutical regimes I am talking about are different from previous public health regimes. In this sense, the Brazilian experiment with AIDS reminds me of the much-celebrated technical control of yellow fever, the bubonic plague, and smallpox in Rio de Janeiro from 1903 to 1906, under the leadership of scientist-administrator Oswaldo Cruz.

In 1900, after returning from his microbiological studies at the Pasteur Institute in France, Cruz was given a position in the national Serum Therapy Laboratory, later named after him. The laboratory's growing technological and research base and rise to international fame with the discovery of Chagas's disease was closely connected to Cruz's successful public health campaign in Rio. As historian Nancy Stepant (1976) has shown, the need to halt disease in the capital was pressing not only in order to improve Brazil's public image abroad, but also to guarantee the flow of much-needed immigrants and capital. Cruz's program tested the nation's ability to be part of the modern world: it replaced the traditional solutions of fumigation and disinfection by a plan that was large scale and very expensive, including systematic extermination of Aedes aegypti mosquitoes, patient isolation, compulsory vaccination, and treatment with serums. Much of the efficacy of this short-lived intervention lay in strong federal financial support, the integration of laboratory science, experimental medicine and public health, and their urban targetedness. The rational-technical control of AIDS that I have been talking about follows this pattern: it integrates science into state policy and experiments with circumscribed populations – its economic sustainability is in question.

The optimism of successfully containing the plagues in Rio, and thereby engendering a limited reality that would stand for a healthy modern Brazil, was counterbalanced, however, by the shocking publication, in 1904, of Euclides da Cunha's classic Or Sertões, translated as Rebellion in the Backlands (1946). A military engineer and journalist, Euclides chronicled a war waged by the national army a few years earlier against an autonomous community made up of mostly landless peasants and former slaves led by a healer, Antonio Conselheiro, in the backlands of the northeastern state of Bahia. The ending of Canudos' settlement and the brutal elimination of thousands of jagunços, as they were called, played a key symbolic role in the spectacle of Brazil's turn of the century political modernization as well – the war was justified in the name of local order, democracy, and of militarily safeguarding the paths of progress.

For Euclides, the war itself became a source of intelligibility of the complex social order of which these abandoned people were a part. He took as his problem to understand and to indict what he called the "barbaric forces of civilization" inasmuch as they actively needed to leave "a third of our people in the heart of our country behind in centuries-old semi-darkness" (1944: 161), where any crime could be committed without being investigated or punished. Euclides counterposed that miserable society, in rags and self-sustaining, with the army of Brazil's modernization, backed by science, armaments, and arts of war derived from Europe. According to him, the same emancipatory science that helps to know and to improve life also helps to kill, particularly in the periphery of civilization, where that science is taken up as the norm by "the blind copyists that we are" (1944: 161). The wretched misery and violence witnessed by Euclides compelled him to question the determinism of a physical anthropological foundation on the existence of a homo americanus, on the supposed degeneracy of "inferior mixed races," and on the destiny of environmental overdetermination: "There is not such a thing as a Brazilian anthropological type... We are condemned to civilization... Our biological evolution demands the guarantee of social evolution" (1944: 54).

How People Become Absent Things

Let me give you a brief sample of a social epidemiological study I carried out in the northeastern state of Bahia. Bahia is the largest state in the Northeast Region, with a population of 12.5 million. Salvador, the capital, has 2.5 million people and is a center of international tourism. Salvador concentrates 70 percent of the total AIDS cases in the state. In 1997, epidemiological reports were already citing a decrease in AIDS incidence in Bahia, and such a decrease was in line with the country's successful containment measures (Dourado et al. 1997a). The AIDS reality I saw exposed in the streets of Salvador and in community-run services contradicts this local and national optimistic epidemiological profile (Dourado et al. 1997b). I learned of a hidden AIDS epidemic by following Dona Conceição, a nurse who every Wednesday noon, aided by some of her religious friends, cooks large pots of food and distributes them to some 120 adults and children with AIDS, living in the abandoned buildings of downtown Salvador and surviving through marginal economies. As Dona Conceição says: "You know, the services never meet the demands, there is always lack." Most of her patients present "AIDS symptoms" and have either been treated in an emergency room, discharged without having recovered, or have received no assistance at all: "I have lost many, but others emerge."

As I was doing an ethnography of all state's AIDS services, out of curiosity I asked a nurse working in the state's surveillance service to check if some of Dona's Conceição's patients were registered in their database. They were not. I was challenged to investigate the public health machinery that structures this absence, all the while producing a rational-technical truth of decreases in AIDS
incidence. I went to the state hospital where most of the abandonados tried to get hospitalized. There, aided by two local epidemiologists, I counted all certificates of people who died with AIDS in the hospital from 1990 to 1996. In doing so, we were reconstructing what was happening in the present. We documented that only 26 percent of all AIDS-related deaths that took place there were actually registered as AIDS cases by the state’s surveillance service.

I was able to identify a series of problems that are occurring at different levels of data collection and analysis, both in the hospitals and in the surveillance service. For example, even though doctors say that they are effectively registering all AIDS cases, many do not register due to sheer neglect or moral contempt. As the state has created a minimum infrastructure for AIDS care, it has not taken strategic steps to improve the sensitivity and speed of its surveillance activities. AIDS cases frequently get lost in the bureaucracy between hospitals and surveillance. In addition, political partisanship obliterates a good flow of information between technicians working at city, state, and national branches of the AIDS Program. Disagreements over diagnostic criteria also make AIDS cases disappear. Given the steady changes in the clinical biomedical knowledge about HIV/AIDS, there is an increasing discrepancy between what the health professionals understand as clinical AIDS and the criteria adopted by the Ministry of Health to define AIDS. Thus, quite often AIDS cases being treated in the public health services, even when they progress to death, are not acknowledged by the state as AIDS cases. Since surveillance technicians do not even keep track of all easily framed AIDS cases, they simply opt not to enter the questionable cases into the databank – thus making impossible even their a posteriori recovery.

The categories traditionally used by epidemiology and by the social sciences to map and interpret the impact of social and economic realities on health–disease–death processes (such as age, race, and individual risk factors, or gender inequalities, sexual culture, and social representations of risk and safety) are insufficient to account for the rational-technical dynamics at work here. Insights from the social studies of science are helpful, to a point (Latour 1987, 1990; Shapin and Schaffer 1985). Bruno Latour, for example, highlights the “cascading” power of scientific representations to socially “draw things together,” thus allowing “harder facts” to be produced (1990: 40, 41). He explicates the “paradox” that “by working on papers alone, on fragile inscriptions that are immensely less than the things from which they are extracted, it is still possible to dominate all things and all people” (1990: 60). Thus, ideas and representations become social technologies in that they function for “accumulating time and space” (1990: 32), because they enable one to present (and therefore control) “absent things” (1990: 27) in a persuasive and efficient way. His caveat: “To take the existence of macro-actors for granted without studying the material that makes them ‘macro,’ is to make both science and society mysterious” (1990: 56). What is missing in a Latourian sociology of science is an account of how historically specific these transactions are, and how scientific and social technologies are combined into governance. The work of Ian Hacking comes to mind.

In his book The Taming of Chance, Ian Hacking (1990) points to the political and moral power of statistical representations, particularly with regards to medical-forensic-political language. Hacking builds upon Michel Foucault’s notion that in modern societies there are two poles where politics takes place. One pole is the individual body, and the other is focused on the biological processes of populations. This polarity between human anatomics and the biopolitics of populations is linked together by intermediary relations. Hacking has identified scientific and technical dynamics that intermediate processes by which “people are made up” (1990: 3; 1999). Hacking’s “dynamic nominalism” states that categories and counting define new classes of people, normalize their ways of being in the world, and also have “consequences for the ways in which we conceive of others and think of our own possibilities and potentialities” (1990: 6). If Hacking examines categories and statistics as making up people, I am concerned in this study with how technical and political dynamics make people invisible and how these dynamics literally impact dying, its experience, distribution, and social representation. As I found out in my ethnography, bureaucratic procedures, informational difficulties, sheer medical neglect and moral contempt, and unresolved disputes over diagnostic criteria all mediate the process by which these people are turned into “absent things.” And I began to call these state and medical procedures and actions “technologies of invisibility.”

Let me show you some numbers. We counted 571 AIDS deaths at the State Hospital between 1990 and 1996. We checked how many of those AIDS cases were registered by the state Surveillance Department. As I mentioned above, we found that only 150 (26 percent) of those AIDS cases were officially registered. The yearly notification rate has varied from 5.6 percent to 34.8 percent, and since 1992 has stabilized around 30 percent (immediately before the decrease of AIDS incidence was first reported; Dourado et al. 1997b). One can argue that this relatively stable registration rate of 30 percent represents the limited AIDS population that the state is ready to structure its services for (see Table 10.1).

Back to the death certificates. We were intrigued: what makes some of these AIDS cases officially visible and the majority not? Is there a bias of selection at work in their registration as AIDS cases?

The next table (see Table 10.2) compares the characteristics of the 150 patients who were registered with the characteristics of the 421 who were not.

I want to call your attention to three statistical facts:

1. Among the total cases analyzed, 297 (52 percent) died during their first hospitalization. One can argue that when these people finally have access to the hospital it is largely in order to die.

2. The percentage of those registered cases that died during the first hospitalization is very different from the percentage of those nonregistered cases that
Table 10.1  Number of deaths of AIDS patients at the AIDS Unit of the State Hospital between 1990 and October 1996, and breakdown by whether or not these patients were registered as AIDS cases by the Bahian Epidemiological Surveillance Service

<table>
<thead>
<tr>
<th>Year of hospitalization</th>
<th>Registered N (%)</th>
<th>Nonregistered N (%)</th>
<th>TOTAL N</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>3 (7.1)</td>
<td>39 (92.9)</td>
<td>42</td>
</tr>
<tr>
<td>1991</td>
<td>4 (5.6)</td>
<td>67 (94.4)</td>
<td>71</td>
</tr>
<tr>
<td>1992</td>
<td>33 (28.7)</td>
<td>82 (71.3)</td>
<td>115</td>
</tr>
<tr>
<td>1993</td>
<td>24 (28.9)</td>
<td>59 (71.1)</td>
<td>83</td>
</tr>
<tr>
<td>1994</td>
<td>32 (32.3)</td>
<td>67 (67.7)</td>
<td>99</td>
</tr>
<tr>
<td>1995</td>
<td>31 (34.8)</td>
<td>58 (65.2)</td>
<td>89</td>
</tr>
<tr>
<td>1996</td>
<td>23 (31.9)</td>
<td>49 (68.1)</td>
<td>72</td>
</tr>
<tr>
<td>TOTAL</td>
<td>150 (26.0)</td>
<td>421 (74.0)</td>
<td>571</td>
</tr>
</tbody>
</table>

Table 10.2  Comparison of characteristics of the 150 patients registered as AIDS cases by the state Surveillance Department with characteristics of the 421 not registered

<table>
<thead>
<tr>
<th>Variables</th>
<th>Registered 150 N (%)</th>
<th>Nonregistered 421 N (%)</th>
<th>$\chi^2$ (value of $p$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Number of hospitalizations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 only</td>
<td>56 (37)</td>
<td>241 (57)</td>
<td>$p &lt; 0.001$</td>
</tr>
<tr>
<td>2 or more</td>
<td>94 (63)</td>
<td>180 (43)</td>
<td></td>
</tr>
<tr>
<td>2 Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>421</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>109 (73)</td>
<td>344 (82)</td>
<td>$p &lt; 0.02$</td>
</tr>
<tr>
<td>Female</td>
<td>41 (27)</td>
<td>77 (18)</td>
<td></td>
</tr>
<tr>
<td>3 IDU</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>43 (29)</td>
<td>111 (26)</td>
<td>N.S.</td>
</tr>
<tr>
<td>4 Sexual transmission</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (male)</td>
<td>60</td>
<td>181</td>
<td></td>
</tr>
<tr>
<td>Homosexual</td>
<td>14 (23)</td>
<td>101 (56)</td>
<td>$p &lt; 0.001$</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>34 (57)</td>
<td>62 (34)</td>
<td>$p &lt; 0.002$</td>
</tr>
<tr>
<td>Bisexual</td>
<td>12 (20)</td>
<td>18 (10)</td>
<td>$p &lt; 0.041$</td>
</tr>
<tr>
<td>5 Origin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>139</td>
<td>381</td>
<td></td>
</tr>
<tr>
<td>Salvador</td>
<td>124 (89)</td>
<td>290 (76)</td>
<td>$p \pm 0.001$</td>
</tr>
<tr>
<td>Interior of Bahia</td>
<td>15 (11)</td>
<td>91 (24)</td>
<td></td>
</tr>
<tr>
<td>6 Age</td>
<td>29/34,40</td>
<td>29/35,40</td>
<td>N.S.</td>
</tr>
</tbody>
</table>

died during their first hospitalization. Among the registered cases, 56 (27 percent) died during the first hospitalization. By contrast, among the 421 nonregistered cases, 241 (57 percent) died during the first hospitalization. This is of very high statistical significance: $p < 0.001$. For people who are not familiar with statistical research, the $\pi$ value is the likelihood that the result of a comparison between two groups is not random – the lower the $\pi$ value, the more scientifically significant the difference is (at least in medical research). In this case, persons who died in their first and last hospitalization have fewer chances of being represented at all.

3 Regarding reporting on sexual behavior: among the 60 male cases who were registered, there is a greater percentage of individuals who reported homosexuality (57 percent) and a lower proportion of individuals who reported homosexuality (23 percent). A reverse scenario is found among the male cases that were not registered (34 percent vs. 56 percent). This is also of high statistical significance: $p < 0.001$. These data indicate another bias of selection: persons who reported themselves as homosexuals also have less chance of being epidemiologically represented.

Interestingly, the AIDS protocols we worked with had no social indicator such as level of education. But let me remind you that these are the poorest of the poor. As the unit’s social worker put it: “These are the patients who live in the gutter.... Sometimes strangers send them here in a taxi, others are brought in by the police. They come in dying, they have bad skin lesions... The ones who recover just return to the streets where they die... They seldom come back for a follow-up. It is unrealistic to demand that a person who lives on the street adhere to treatment. They never heal.”

To sum up the overall rationale at work here, these dynamics of minimum registraion of around 30 percent produce norms of intervention aimed at a specific target group: a self-registered seropositive population. Specialized health care is provided to those who identify themselves as AIDS cases in an early stage of infection at a public institution, and who independently search for regular treatment. This specific population is, at the same time, conceived a priori and takes shape through this intervention - they are what I call AIDS or biomedical citizens. This is the reality that appears in the optimistic epidemiological reports showing a decrease of AIDS incidence in Bahia. Individuals who cannot be framed within this planned demand and within this self-selecting conception of public health remain outside any official registers and do not receive intervention. The majority of these nonregistered cases are persons who are only identified as having AIDS when they are dying, in their first and last hospitalization. Meanwhile, the short-term care of these dying marginal patients is relegated to a mostly sporadic street charity, like that of Dona Conceição.

My colleagues and I submitted a report to the Bahian Health Division informing them of this hidden AIDS epidemic. I learned later that this report was
suppressed. It was within this kind of unreformed and publicly discredited regional politics that the antiretroviral policy came into effect; it is in these repressive local force fields and moral economies that the sustainability of the AIDS policy remains in question.

The Politics of Death

I am interested in the complexity that is revealed as the anthropologist returns to the field. Then one sees more clearly emerging changes and the making of intractable sameness. The returning longitudinal engagement is a key methodological and ethical move for anthropology, history, and critique. It clarifies how science and technology are integral with local worlds and politics. At stake is the temporality of knowledge, institutions, technology, money, and lives. In 2000 and 2001 I returned to Salvador where the antiretroviral mobilization and distribution system was also said to be operating well. Recall the three images I began with: the dying city, the absent people and bodiless citizens, and the disciplinary and automatic functionings of power. Juxtapose with those images the following ones. The central HIV testing center has been upgraded and there is a massive influx of poor and middle-class people, a new testing population. Next door, there is a new and sophisticated AIDS outpatient clinic under construction. Patients here, their social status known and ability to adhere proven, will be screened for all kinds of phase III and IV clinical trials run by new partnerships between the local Federal University and multinational pharmaceutical companies. Back at the state’s official AIDS unit, things are the same: still only 16 beds, care reduced to a minimum, and the dying in the corridors as in the streets is routine.

In this work, I am rethinking one of Foucault’s maxims that biopower dominated mortality rather than death: “power does not know death anymore and therefore must abandon it” (1992: 177). As I have been demonstrating, the management of death among the poorest is concomitant with the successful control of mortality as articulated by Brazil’s new biopolitics. Here, letting die is a technical and political action, contiguous with the scientific, medical, and pastoral power that makes live.

Following Hannah Arendt and Michel Foucault, philosopher Giorgio Agamben argues that the original political element of sovereign power in Western democracies is “not simple natural life, but life exposed to death” (1998: 24). In The Human Condition (1958), Arendt argued that after World War II political action has been increasingly focused on the control of natural life, biological processes. Homo faber gave way to homo laborans, the being concerned with physiological existence. Science has played a key role in this transformation: “In other words, the process which, as we saw, invaded the natural sciences through the experiment, through the attempt to imitate under artificial conditions the process of ‘making’ by which a natural thing came into existence, serves as well or even better as the principle for doing in the realm of human affairs” (1958: 299). This happens within the fabric of Christian societies – and this is so because the fundamental belief in the sacredness of life has survived. “The only thing that could now be potentially immortal, as immortal as the body politic in Antiquity and as individual life during the Middle Ages, was life itself; that is, the possibly everlasting life process of the species mankind” (1958: 321). As Arendt concludes: “The loss of human experience involved in this development is extraordinarily striking” (1958: 321).

Agamben locates the beginnings of the structures of sovereign administration of bare life in ancient Roman law, particularly in the figure of homo sacer. The “sacred man” was the one convicted as a criminal, with the capacity to be killed (without legal charge of homicide) but not sacrificed. This particular form of life was caught in a double exception. “Just as the law, in the sovereign exception, applies to the exceptional case in no longer applying and in withdrawing from it, so homo sacer belongs to God in the form of insacriable and is included in the community in the form of being able to be killed. Life that cannot be sacrificed and yet may be killed is sacred life” (1998: 82). Agamben argues that such an embodied violence, subtracted from human and divine law, opened up a new sphere of legitimate human action. This action is a human extension of the state of exception, that proper political space of the West: “The sovereign is the one with respect to whom all men are potentially homines sacrati, and homo sacer is the one with respect to whom all men act as sovereigns” (1998: 84).

Agamben points out that the determinant structure of our modern inherited ways of ordering public spaces and political relations is in relation to a ban. “The ban is essentially the power of delivering something over to itself, which is to say, the power of maintaining itself in relation to something presupposed as non-relational. What has been banned is delivered over to its own separateness and, at the same time, consigned to the mercy of the one who abandons it – at once excluded and included, removed and at the same time captured” (1998: 109–110). In the body of homo sacer political and social forms of life have entered into a symbiosis with death without it belonging to the world of the decaxed. The original political element of sovereign power is “not simple natural life, but life exposed to death” (1998: 88).

As an anthropologist, I am particularly interested in the ability of medicine and politics to engender new sorts of populations in the field and to make some people an invisible part of the equation. As my Bahian investigation reveals, marginal and diseased groups are included in the social order through their dying and as if dying had been self-generated. By self-generated I mean that these noncitizens only become partially visible in the health system when they are dying; they are traced as “drugs addicts,” “robbers,” “prostitutes,” labels which allow them to be socially blamed for their dying. They have erased their origins as well as the complex social causes that exacerbate infections and immune depressions.
The existence of states of exception within the restructuring of Brazil’s economy, state, and public health is a complex political and ethical question. In such states of exception, the person is presupposed as nonrelational and stays at the mercy of the individuals and institutions that at one point or another abandon him or her. He or she is, on the one hand, excluded from family and state action and, on the other, socially included either as a new epidemiological risk vector or through a public dying (Bielli 1999, 2001). The abandoned person with AIDS inhabits a zone of indifference in which the concept of the human is a posthumous one and the notion of a perpetrator or of accountability has been suspended.

In his insightful book Seeing Like a State, James Scott illustrates why some of the major projects to improve the human condition in the twentieth century have failed and produced tragedy: “The lack of context and particularity is not an oversight; it is the necessary first premise of any large-scale planning exercise” (1998: 346). “Making people invisible,” I argue, has become an indispensable tool of containment (a structured nonintervention) within the calculations of life processes that are here and now at the center of governance: Who shall live? Who shall die? And at what cost?

Extending Life

A few of the AIDS abandonados are selected out for social regeneration in community-run sites called “houses of support.” In order to uncover this different destiny, I undertook longitudinal work at Caasah, a community-based care center for some of the marginal and poor living with AIDS in Salvador (Bielli 1999). Caasah was founded in 1992, when a group of marginals squatted an abandoned maternity ward in the outskirts of Salvador. The squatters called themselves “revolutionary” and chose a trained nurse to administer their new house. City officials and local AIDS activists helped Caasah to gain legal status, and by 1993 it became a nongovernmental organization. With 30 inhabitants, Caasah then successfully applied with two projects to the National AIDS Program. The core maintenance of the institution, its technical upgrading and “civilizing processes” were now closely tied to the funds channeled from the World Bank loan. Indeed, Caasah and similar initiatives are actually being incorporated by the state and qualified as health services. Throughout the country, pastoral institutions such as Caasah triage AIDS pensions and antiretroviral therapies to some of the poorest with AIDS. As of 2000, 100 of the country’s 480 AIDS NGOs were houses of support. The question of where to put the diseased poor has fallen out of the state’s purview and has become a pastoral undertaking. In order to enter these institutions, the abandonados have to break with their past and addictions. They start to distinguish themselves from the “living dead” of the street environment they left behind and develop a biotechnical biography.

Over the years of my research, I produced an archive of Caasah’s institutional history and recorded the inhabitants’ collective and individual life histories. They experience accelerated time, in terms of both social and biological change. Beginning in 1994, strict disciplinary mechanisms led to the expulsion of unruly patients. A reduced group passed through an intense process of normalization coordinated by a therapist sent by the National AIDS Program in 1995. By the end of that year, concerns about internal violence, aggressions, and drug trade and consumption were replaced by concerns for hygiene and house maintenance. The next move involved medicalization, under the guidance of a newly hired nurse. He established an infirmary post with a pharmacy and a triage room.

Caasah had dramatically changed by 1996. The main corridor was now crowded with nursing trainees and volunteers wearing white lab-coats carrying trays with medicine to their patients. The marginal patients had either left or had died, and a higher number of working poor were now living there. The residents had acquired a new biomedical conscience—“culture,” as Caasah’s director told me—as they were managing their own health. “With time we domesticated them.” I could see that the healthy patients followed very closely each other’s debilitation process, and were actually obliged to help to care for the ones dying in the triage room. In this case, the dying abandonados still have a last social function: they are part of the Bidding (self-formation) process of the AIDS citizens. As the director puts it: “Handling the dying is helpful for the residents to see what will happen to them if they don’t change their minds and follow their treatments.” Dark-skinned and with contagious scabies, Evangélio understands himself as the pathogen of the healthy AIDS citizens: “I keep saying to myself, ‘My God, I was not born like this, will this be my skin to the end? I feel very isolated, as if I were in a prison. I see people passing by and wishing me dead. They give me tranquillizers... All these things leave me in a sad psychosis.”

As Caasah’s inhabitants put their drives into place, so to speak, their biological condition becomes the locus of concentration and fabrication. Many refer to the HIV virus as “my little animal.” Some patients used to say, “I want to let the little animal sleep in me.” I frequently heard comments such as, “The moment you fall back into what you were and stop taking your treatment, the virus occupies your place. And the virus only occupies the place because you let it.” Many live, in their own words, “in a kind of constant battle.” They know they are trapped between two destinies: dying of AIDS like the poor and marginal, that is, “animalized,” and the possibility of living pharmacologically into a future, thereby letting the animal sleep, and preventing it from consuming the flesh. With the availability of anti-HIV drugs, health is increasingly seen as a problem of treatment adherence or of individual misconduct.

Evilásio is a single man, illiterate, and a carpenter by profession. He said he did not know he had AIDS, even though he had been once to a hospital. As his body
began to waste, he retreated into his shack and was found almost dead by neighbors, who finally dropped him at Caasah. Evilásio quickly learned the norms of the house and now "accumulates health": "The nurses have nothing bad to say about me... I can tell you that for me Caasah is the house of God." Valquiriane, Caasah’s first patient to have successfully taken the combined therapy, knows that she is now "another person." As she puts it: "I have been born again; it is not such a bad thing to have HIV. It’s like not having money. And in Brazil everybody experiences that."

The new medical and political reality lived by Caasah’s inhabitants adds to Hannah Arendt’s insights on the determinations of the present human condition. Arendt identified a modern political process that progressively eliminates the possibility of human fulfilment in the public realm, excluding masses and reducing them to the condition of animal laborans, whose only activity is that of biological preservation (1958: 320–325). This preservation is an individual concern; this metabolism is superfluous to the state and to society at large. "They begin to belong to the human race in much the same way as animals belong to a specific animal species" (1973: 302). I am telling a somewhat different story. What is distinctive in Caasah is that the diseased biology of these abandonados is also a technical means of social inclusion. While these people learn new scientific knowledge and navigate through new laboratories and treatment regimes, they force an inclusion into a very sophisticated and selective form of governance. Against an expanding discourse of human rights, we are here confronted with the limits of the official structures whereby these rights are realized, biologically speaking, but only on a selective basis, and the emergence of a new political economy of pharmaceuticals.

Pharmaceutical Futures

In spite of its internal paradoxes, the fact is that the Brazilian AIDS policy keeps thriving and is now setting some of the terms of highly contested transnational economic processes, as well as informing new forms of pathbreaking international medical activism. In November 2001, the World Trade Organization (WTO) issued a declaration, originally proposed by Brazil, stating that the international protection of patents was indefensible in the face of public health crises. The declaration reads: "We are of the firm opinion that [TRIPS] should be interpreted and implemented in a way which is consistent with the right of WTO members to protect public health and in particular to assure medicines for all" (AIDS Imprensa 2001). The immediate implications of these new developments need to be carefully followed as they redefine the international pharmaceutical contract, as they challenge poor countries to work on their public health infrastructure to replicate the Brazilian model, as Brazil shares its AIDS managerial and technological know-how with Portuguese-speaking countries in Africa, and as they might also make possible for Brazil to secure new trade concessions from the United States, or even for India to become a key player in the global market of generic drugs. We are also challenged to continue to ethnographically chart, understand, and politicize the complex and often contradictory ways in which neoliberalizing policies, state presence, and health and wellbeing are forged in local worlds where biotechnology and scarcity exist side by side. The constitution of biomedical forms of citizenship for marginal and poor AIDS patients happens within various networks of care (public/non-governmental/pastoral) that are by and large reduced to triage, and the struggle over life extension and social death is played out on the very register of humanism. One’s mere worthiness to exist, one’s claim to life, and one’s relation to what counts as the reality of the world passes through what is considered to be human now – and this is a site of intense medical-scientific and legal dispute, and of moral and subjective fabrication. Between the loss of an old working concept of humanism and of belonging, if solely to the streets, and the installment of a new one, the world is experienced as vanishing to many and to others as a pharmacetical possibility.

Notes

1 This specific excerpt is taken from Michel Foucault’s reading of Oedipus in “Truth and Juridical Forms” (2000).
2 I draw from Giorgio Agamben’s interpretation of Leibniz’s figure as presented in the seminar “Thresholds: Thinking in the State of Exception” taught with Daniel Heller-Roazen at Princeton University in fall 2001.
3 Since AIDS first appeared in the early 1980s, the pandemic has killed approximately 22 million people worldwide, 17 million in Africa alone, and has produced more than 13 million orphans. In 2002 an estimated 36 million people were living with HIV, 95 percent of them in low-income countries; and 16 thousand new infections were occurring everyday worldwide. The pandemic has indeed become a major source of social, economic, and political instability, particularly in the developing world where therapies remain largely inaccessible. After the United States, Brazil has the second largest official number of HIV infections in the Western hemisphere.
6 In 1985, the first GAPA (Grupo de Apoio à Prevenção à AIDS) was created in São Paulo, and it would soon have independent extensions in Porto Alegre and Salvador, for example. GAPAs worked on prevention and also mediated the treatment and legal demands of AIDS victims. Also in São Paulo in 1985, transvestite Brenda Lee founded
the country’s first *casa de apoio* (house of support) for dying patients. In 1986, activist Herbert Daniel created ABIA, the Brazilian Interdisciplinary AIDS Association, which played a key role in the production of AIDS knowledge and dissemination. In 1989, the group Pella Vida was formed in Rio de Janeiro and São Paulo (it was another very important outgrowth of the work of Daniel), composed mostly of HIV-positive people and aimed at their medical concerns.

7 Teresa Caldeira (2002) elaborates on police violence and on popular demands for the death penalty in light of Brazil’s democratization and international cultures of human rights.

8 See Adriana Petryna’s analysis of the emergence of biological forms of citizenship in the Chernobyl aftermath (2002).

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