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Second Edition

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OXFORD
UNIVERSITY PRESS

2009

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The Brazilian Response to AIDS and the Pharmaceuticalization of Global Health

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Introduction

Brazil is known for its stark socioeconomic inequalities and for its persistent challenges in development. Yet, against all odds, Brazil has invented a public way of treating AIDS. In 1996, it became the first developing country to adopt an official policy that provided universal access to antiretroviral drugs (ARVs), about 5 years before global policy discussions moved from a framework that focused solely on prevention to one that incorporated universal treatment (Biehl 2004; Calvão 2000; Levi and Vitória 2002). The AIDS treatment policy was made possible by an unexpected alliance of activists, government reformers, development agencies, and the pharmaceutical industry. About 200,000 Brazilians are currently taking ARVs that are paid for by the government, and this policy is widely touted as a model for stemming the AIDS crisis worldwide (Berkman, Garcia, Muñoz-Laboy, Paiva, and Parker 2005; Okie 2006).

This chapter examines the Brazilian response to AIDS, revealing the possibilities as well as the inequalities that accompany a magic-bullet approach to health care. It moves between a social analysis of the institutional practices shaping this therapeutic policy and an account of the experiences of people affected by it, particularly in impoverished urban settings where the epidemic is spreading most rapidly. I draw from open-ended interviews I carried out

with activists, policymakers, health professionals, and corporate actors in both Brazil and the United States between 2000 and 2005. I also draw from my longitudinal study of the lives of marginalized AIDS patients and of the work of grassroots care services in the northeastern city of Salvador. I chronicled the activities of Dona Conceição, a philanthropist helping homeless AIDS patients, and I carried out participant observation at a “house of support” called Caasah. I undertook this study between 1995 and 2005 for a total of 20 months. In 1997, I collected the life stories of 22 AIDS patients who lived at Caasah and I have charted their life trajectories before and after access to antiretroviral therapies (Biehl 2006). All these materials are part of my ethnography *Will to Live: AIDS Therapies and the Politics of Survival* (2007).

Some of the questions that guided my investigation include which public health values and political and technological practices make this therapeutic policy possible, and what guarantees its sustainability? How has the AIDS policy become a kind of public good, emblematic of the state’s universal reach, even though it is not enjoyed by all citizens? What networks of care emerge around the distribution of lifesaving drugs? How do the poorest understand and negotiate medical services? How do their lifestyles and social support systems influence treatment adherence? What happens to poverty as these individual sufferers engage the pharmaceutical control of AIDS? What do these struggles over drug access and survival say about politics, citizenship, and equity on the ground and globally?

Universal Access to Lifesaving Therapies

Amidst denial, stigma, and inaction, AIDS became the first major epidemic of present-day globalization. Of more than 33 million people estimated to be HIV-infected worldwide, 95% live in middle- or low-income countries, causing life expectancy to drop dramatically in those countries worst hit. In late 2003, with only about 400,000 people receiving treatment, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) announced their goal of having 3 million HIV-positive people on antiretroviral therapy by 2005 (known as the “3 by 5” campaign). The results have been mixed, but by any account Brazil has been a leader in the effort to universalize access to treatment. By the end of 2004, the number of people on ARVs had increased to 700,000 globally—in the developing world, this figure stood at 300,000, of which half the people lived in Brazil. And when the deadline arrived at the end of 2005, with an estimated 6.5 million people requiring treatment, 1.2 million were on ARVs—encouraging, but still short of the target. Brazil, with less than 3% of the world’s HIV/AIDS cases, still accounted for nearly 15% of people on ARVs.¹

Brazil is the epicenter of the HIV/AIDS epidemic in South America and accounts for 57% of all AIDS cases in Latin America and the Caribbean.

The country's first AIDS case was diagnosed (retrospectively) in 1980 and through mid-2002 the Ministry of Health had reported nearly 240,000 cumulative cases. HIV prevalence in Brazil is higher than in most of its neighbors, although this is in part due to more accurate reporting (Berkman et al. 2005; Castilho and Cherquer 1997). At the end of 2001, an estimated 610,000 individuals were living with HIV/AIDS (an adult prevalence of 0.7%, about half of what had been projected). Social epidemiological studies show considerable heterogeneity in HIV infection rates, with large numbers infected among vulnerable populations and a fast-growing number of heterosexual transmissions (Bastos and Barcellos 1995). In 1998, 18% of sex workers tested in São Paulo were HIV-positive, and in certain areas of the country, intravenous drug users contributed almost 50% of all AIDS cases. Since 1998, the death rate from AIDS has steadily declined, an achievement attributed to the country's treatment policy (Dourado, Veras, Barreira, and de Brito 2006).

Throughout the 1990s, a range of different groups and institutions—activists and local nongovernmental organizations (NGOs), central and regional governments, and grassroots organizations, along with development agencies such as the World Bank—came together, helping to address what was earlier perceived to be a hopeless situation (Bastos 1999; Parker 1994; Parker, Galvão, and Bessa 1999). This combination of social organization and education, political will (at various levels of government), and international cooperation made it possible for Brazil to overcome AIDS denial and to respond to an imminent crisis in a timely and efficient way. AIDS activists and progressive health professionals migrated into state institutions and actively participated in policy making (Parker 1997). They showed creativity in the design of prevention work and audacity in solving the problem of access to AIDS treatment. In their view, the prices pharmaceutical companies had set for ARVs and the protection they received from intellectual property rights laws and the World Trade Organization (WTO) had artificially put these drugs out of reach of the global poor. After framing the demand for access to ARVs as a human right, in accordance with the country's constitutional right to health, activists lobbied for specific legislation to make the drugs universally available.

The Brazilian government was able to reduce treatment costs by reverse engineering ARVs and promoting the production of generics in both public- and private-sector laboratories (Cassier and Correa 2003). Had an infrastructure for the production of generics not been in place, the story being told today would probably be different. For its part, the Health Ministry also negotiated substantial drug price reductions from pharmaceutical companies by threatening to issue compulsory licenses for patented drugs. Media campaigns publicized these actions, generating strong national and international support (Galvão 2002; Serra 2004). The result—a policy of drugs for all—has dramatically improved the quality of life of the patients covered. AIDS treatment has

been incorporated into the country's ailing unified health-care system (Sistema Único de Saúde, SUS) and, according to the Health Ministry, both AIDS mortality and the use of AIDS-related hospital services have subsequently fallen by 70% (Ministério da Saúde 2002). Brazil's treatment rollout has become an inspiration for international activism and a challenge for the governments of other poor countries devastated by the AIDS pandemic. This policy challenges the perception that treating AIDS in resource-poor settings is economically unfeasible, and it calls our attention to the possible ways in which lifesaving drugs can be integrated into public policy even in the absence of an optimal health infrastructure.

By 2000, the Brazilian AIDS Program had been named by UNAIDS as the best in the developing world, and in 2003 it received the Gates Award for Global Health. Brazil is now sharing its know-how in a range of ways. It has taken on a leadership role in the WHO's AIDS program and it is supporting international networks aimed at facilitating treatment access and technological cooperation on HIV/AIDS. In the past years, the Brazilian government has also been leading developing nations in WTO deliberations over a flexible balance between patent rights and public health needs. Practically speaking, Brazil opened channels for horizontal collaborations among developing nations, and devised political mechanisms (as fleeting and fragile as they may be) for poor countries to level out some of the pervasive structural inequalities that place their populations at increased risk and continued ill health.

Persistent Inequalities and Grassroots Health Services

The medical accountability at stake in this innovative policy has drastic implications for Brazil's 50 million urban poor, either indigent or making their living through informal and marginal economies. By and large, they gain some public attention during political elections—even then only in the most general terms—and through the limited aid of international agencies. Through AIDS, however, new fields of exchange and possibility have emerged.

I was in the coastal city of Salvador (the capital of the northeastern state of Bahia) conducting fieldwork when AIDS therapies began to be widely available in early 1997. Considered by many as “the African heart of Brazil,” Salvador was the country's capital until 1763. A center of international tourism, today Salvador has an estimated population of 2.5 million, with more than 40% of families living below the country's poverty line. At the time of my fieldwork, local health officials claimed that AIDS incidence was on the decline in both the city and the region, ostensibly in line with the country's successful control policy. But the AIDS reality one could readily see in the streets of Salvador contradicted this profile. A large number of AIDS sufferers

remained epidemiologically and medically unaccounted for, thereafter dying in abandonment (Biehl 2005). Meanwhile, community-run initiatives provided limited care for some of the poorest and the sickest.

Every Wednesday at noon, Dona Conceição, a 50-year-old nurse, cooked large pans of food and, with the help of her religious friends, handed it out to dozens of poor people and families who lived with AIDS and very little else in the abandoned corners of the city's historical compound known as the Pelourinho (*Pillory*)—once a place where African captives were auctioned and rebellious slaves punished. Today it is a lively cultural heritage center. She provided free meals and some care (medication, clothing, and rent aid) to a total of 110 adults, most of them involved in prostitution and drug dealing, and to their children. As Dona Conceição put it, “Medical services never meet the demands and civil society has abandoned them. They are at the margins of law and life. I give them a little comfort and help alleviate things a bit. I am tied to them in spirit.” Even though she had some support from her extended family and friends, Dona Conceição had to generate money for her AIDS work on her own (mostly through handicrafts sales and donation campaigns).

I talked to Dona Conceição's “street patients” on several occasions. Soft-spoken Jorge Araújo said that he was born on January 1, 1963. “I will not lie to you, I injected drugs, and I have AIDS,” he told me without hesitation. “I abused drugs and myself. I had to amputate my left leg. When I got to the hospital it was too late. And on top of losing the leg they told me I had AIDS.” Jorge had lived by himself and on the streets since the age of 14: “I left home because of my stepfather; we didn't get along. I did little jobs, here and there, sold drugs. I think it is a thing of destiny, right?” At some point, he lived with an older woman and had a child, but he eventually left them. “If I kept thinking about AIDS, I would already be dead. I carry out my life as God wants it. One must forget. One cannot put in one's mind that one is the disease. If we dwell on the disease, then one starts to say ‘Maybe I should not do this or eat that for it will harm me’ and then one is left with even less. To be a patient one needs things. What is there here to have?”

One should not expect these patients to adhere to medical treatments, says Dona Conceição, because “they just use medication until they recover.” And she did not blame them: “How can they comply if they live on the streets? Until they have a home, no treatment will work.” Dona Conceição did not judge her street patients and their actions in terms of right or wrong, in terms of normality or pathology; she understood that structural violence² compounded substance- and self-abuse. In doing so, she implicitly made their condition a public affair, a Brazilian social symptom, I thought. But to complicate things further, she refused to treat them as a collective, and that's what drew them to her. She helped them individualize, and she literally struggled in their place: “Each one has a history, a life left behind. Jorge suffers emotionally—all the

discrimination he goes through, and he is unable to overcome his personal failures. He does not struggle for health; I struggle for him.” How, I wondered, would the antiretroviral rollout fare in this context of multiple scarcities and spurious regional politics? How would the most vulnerable transform a death sentence into a chronic disease? What social experimentation could make such medical transformation possible?

Caasah, a focal point of my research, was founded in 1992, when a group of homeless AIDS patients, former prostitutes, transvestites, and drug users (Jorge was among them) squatted in an abandoned hospital formerly run by the Red Cross. “Caasah had no government,” recalled Celeste Gomes, Caasah's president.³ “They did whatever they wanted in here. Everybody had sex with everybody, they were using drugs. There were fights with knives and broken bottles, and police officials were threatening to kick us out.” Soon, Caasah became a nongovernmental organization (NGO) and began to receive funding from a World Bank loan disbursed through the Brazilian government. By 1994, eviction threats had ceased, and the service had gathered community support for basic maintenance. Caasah had also formalized partnerships with municipal and provincial Health Secretariats, buttressed by strategic exchanges with hospitals and AIDS NGOs. Throughout the country, other “houses of support” (*casas de apoio*) like Caasah negotiate the relationship between AIDS patients and the haphazard, limited public health-care infrastructure. By 2000, at least 100 of the country's 500 registered AIDS NGOs were houses of support. To belong to these grassroots services, people must break with their old habits, communities, and routines as they forge new lives.

By the mid-1990s, the unruly patients in Caasah had been ejected. “I couldn't stand being locked in. I like to play around,” Jorge told me. A smaller version of the group began to undergo an intense process of resocialization mediated by psychologists and nurses. Jorge and about 80 other outpatients remained eligible for monthly food aid. Patients who wanted to stay in the institution had to change their antisocial behaviors and adhere to medical treatments. Caasah now had a reasonably well-equipped infirmary, with a triage room and a pharmacy. Religious groups visited the place on a regular basis and many residents adopted religion as an alternative value system. As Edimilson, a former intravenous drug user and petty thief, put it, “In Caasah we don't just have AIDS—we have God.” According to Celeste, “With time, we domesticated them. They had no knowledge whatsoever, and we changed this doomed sense of ‘I will die.’ Today they feel normal, like us, they can do any activity, they just have to care not to develop the disease. We showed them the importance of using medication. Now they have this conscience, and they fight for their lives.”

Rose's left hand was atrophied, and she limped. “It is all from drug use. I was crazy. I went to the street, to a bar, left with a client, did his game, and

drugged myself with the money". Rose and other healthy patients in Caasah repeatedly pointed to the marks on their bodies as images of past misdeeds, as if they were now in another place, seeing and judging their past selves from a photographic distance. "Ah, now I see. If I only had thought then the way I think now."

Rose grew up in the interior and was expelled from home at the age of 13, after she became pregnant. She moved into a red light district at the Pelourinho. By the end of 1993, Rose learned that she was both pregnant and HIV-positive. A physician who did volunteer work among prostitutes arranged Rose's move to Caasah. One by one, Rose gave up her children for adoption. The newborn girl was adopted by Naiara, Caasah's vice president, and her little boy was adopted by Professor Carlos, the chief nurse. "What else could I have done? I couldn't give them a house. I also thought that I would not live much longer." But Rose has lived longer than she expected. For 4 years, she had been off illegal substances. She had remained asymptomatic, had become literate, and had learned to make handicrafts. At that time, she was involved with Jorge Ramos, another resident, and was beginning to take ARVs. "I take life in here as if it were a family, the family I did not have," she stated.

Caasah's residents and administrators constituted a viable public that effectively sustained itself in novel interactions with governmental institutions and local AIDS services. Instead of succumbing to the factors that predisposed them to nonadherence to treatment (such as poverty and drug addiction), residents used their "disadvantages" to create the AIDS-friendly environment that is necessary to accumulate health.⁴ In this "proxy family" people did not have to worry about the stigma that came with having AIDS "on the outside," and there was a scheduled routine and an infrastructure that made it easier to integrate drug regimens into the everyday life (Abadia-Barrero and Castro 2006). The right to health was group-privatized, and an intense process of individuation—"salvation from my previous life," as some put it—and a spirit of competition with fellow residents motivated treatment adherence as well.

"Did you ever see an AIDS patient in here hoping for the other's good?" Evangelvaldo asked me as he was being quarantined because of his scabies. Residents constantly denounced each other's faults and demanded the rigorous application of the law: "Is there a law? Where is it? Why is it not being applied?" The others' misbehavior was also a measure of their own progress, a measure of their own change and self-control. "I am not like him." "He did it to himself, and now wants another chance." Money was also at stake. The administration was mediating the extremely bureaucratized application for AIDS disability pensions, and priority was given to those residents who showed change. Well-behaved and compliant patients were also allowed to help in the storage room, where they then had priority in choosing clothing for themselves and for family members living outside.

I have chronicled life in and out of Caasah for more than 10 years, and at the end of the chapter I will take the reader back there to see what has happened to this "house" and its residents over time. AIDS therapies are now embedded in local worlds, and hundreds of medico-pastoral institutions of care similar to Caasah help to make AIDS a chronic disease also among the poor. Medicines have indeed become key elements in state-civil society relations. But this is not a top-down biopolitical form of control. The government is not using AIDS therapies and houses of support as "techniques . . . to govern populations and manage individual bodies" (Nguyen 2005:126). Poor AIDS populations are rather temporarily organized through particular and highly contested engagements with what the state has made pharmaceutically available. And as I will show at the end of the chapter, the political game here is one of self-identification, and it involves a new economics of survival.

A Political Economy of Pharmaceuticals

Brazil's response to AIDS "is a microcosm of a new state-society partnership," Fernando Henrique Cardoso, Brazil's former president (1995–2002) and the country's most prominent sociologist, stated in an interview with me in May 2003: "I always said that we needed to have a porous state so that society could have room for action in it, and that's what happened with AIDS."⁵ I met with Cardoso in Princeton, at the Institute for Advanced Study, where he was participating in a meeting of the board of trustees. After leaving the presidency, Cardoso had been traveling the international lecture circuit and had taken a professorship at Brown University. He had no qualms about extrapolating, using the AIDS treatment policy as evidence of the "success" of his state reform agenda—a state open to civil society, decentralized, fostering partnerships for the delivery of services, efficient, ethical, and, if activated, having a universal reach. "Government and social movement practically fused. Brazilian society now organizes itself and acts on its own behalf."

This new state-society synergy reflected in the country's AIDS Program has developed in the wake of Brazil's democratization and the state's attempt to position itself strategically in the context of globalization. Cardoso argued, "We cannot do politics as if globalization did not exist. One must see and decide in practice what is good and what is bad about it. This new phase of capitalism limits all states, of course, including the United States, but it also opens up new perspectives for states." Cardoso said that both he and the new president Luis Inácio Lula da Silva from the Workers' Party (Partido dos Trabalhadores) "in the end say the same thing." That is, "that globalization is asymmetric and that it does not eliminate the differences imposed on nations. So we have to take concrete steps toward decreasing this asymmetry,

mainly at the trade level so that we can have access to markets, and also to the control financing mechanisms." He made the case that Lula's government was basically following the same "ultra-orthodox" economic line of his administration—but that, "surprisingly," the new government lagged in social program innovation: "The proposals they have are centralized, very vague, mismanaged, and don't match with what Brazil already is." Cardoso was proud of the ways the AIDS Program—with its multisectoral partnerships and high-tech delivery capacity—had pushed the envelope of what was governmentally possible.

"The idea that nothing can be done because rich countries are stronger is generally true, but not always," stated Cardoso. "You can fight and, in the process, gain some advantages. You must penetrate all international spheres, try to influence and branch out. The question of solidarity must be continuously addressed." Brazil's struggle for drug price reduction, he says, "shows that under certain conditions you can gain international support to change things. All the nongovernmental work, global public opinion, change in legislation, and struggle over patents are evidence of new forms of governmentality in action . . . thereby engineering something else, producing a new world." The rhetoric of state agency and the abstractions that Cardoso articulated—mobilized civil society and activism within the state—are part of a new political discourse. This language belongs to a public sphere strongly influenced by social scientists, as well as by politicians who do not want to take responsibility for their decisions to conform to the norms of globalization. For example, Cardoso makes no specific reference to the measures his administration took to open the economy such as changes in intellectual property legislation and the privatization of state industries. This political discourse does not acknowledge the economic factors and value systems that are built into policy making today.

As with all things political and economic, the reality underlying the AIDS policy is convoluted, dynamic, and filled with gaps. The politicians involved in the making of the AIDS policy were consciously engaged in projects to reform the relationship between the state and society, as well as the scope of governance, as Brazil molded itself to a global market economy. And one of my central arguments is that behind the concept *model policy* stands a new political economy of pharmaceuticals. Just a few months before approving the AIDS treatment law in November 1996, the Brazilian government had given in to industry pressures to enshrine strong patent protections in law. Brazil was at the forefront of developing countries that supported the creation of the WTO, and it had signed the Trade-Related Aspects of Intellectual Property Rights treaty (TRIPS) in December 1994. Parallel to the new patent legislation, pharmaceutical imports to Brazil had increased substantially. Between 1995 and 1997, the trade deficit in pharmaceutical products jumped from \$410 million to approximately \$1.3 billion (Bermudez, Epsztein, Oliveira, and Hasenclever 2000).

Moreover, in his pragmatic approach to globalization, Cardoso articulates a market concept of society. For him, citizens are consumers who have "interests" rather than "needs." The government does not actively search out particular problems or areas of need to attend to—that is the work of mobilized interest groups. "There has never before been so much NGO action within the government as has occurred in the past ten years. In all our social programs there was some kind of social movement involved." According to Cardoso, these elements of cooperation and nongovernmental involvement are key for maximizing the state's regulatory power and equity in the face of the market's agency in resource allocation and benefits. The work of NGOs and their international counterparts gives voice to specific mobilized communities and helps to consolidate public actions that are "wider and more efficacious than state action."

In these conditions, lawmaking is the main arena of state action—and putting new laws into practice is an activist matter. Cardoso lauds the signing of the AIDS treatment law, given that "They said nothing would pass." In mobilizing for a law and approving it, the state realizes its social contract. In Cardoso's vision, specific policies and legislation replace a wider social contract. In practice, people have to engage with lawmaking and jurisprudence to be seen by the state and the implementation of the law remains subject to a whole range of exclusionary dynamics related to economic considerations and specific social pressure. The AIDS treatment policy, one can argue, illuminates what was at stake in past political decisions and economic maneuvers and how they are being remediated by novel state–medical–market initiatives.

The Pharmaceuticalization of Public Health

Global pharmaceutical sales reached \$602 billion in 2005—a growth of 7% from the previous year. According to IMS Health, the world's leading market intelligence firm: "As growth in mature markets moderates, industry attention is shifting to smaller, developing markets that are performing exceptionally well."⁶ This is the case of Brazil, now the 11th largest pharmaceutical market in the world (see Bermudez 1995). Currently, some 550 pharmaceutical firms (including laboratories, importers, and distributors) operate in Brazil and compete for a slice of its lucrative pharmaceutical market, which in 2005 reached \$10 billion. By 2010, the developing world is expected to account for approximately 26% of the world pharmaceutical market in value, compared with 14.5% in 1999.

Dr. Radames, a Brazilian infectious disease specialist and adviser to the WHO explained to me: "Pharmaceutical companies had already recouped their research investment with the sell-off of AIDS drugs in the United States and Europe and now with Brazil, they had a new fixed market and, even if they had to lower prices, they had some unforeseen return. If things worked out

in Brazil, new AIDS markets could be opened in Asia and perhaps in Africa” (personal communication, August 2000).

Dr. Jones, an executive of a pharmaceutical multinational that sells ARVs to the Brazilian government, does not put things so explicitly, but he asserts that “patents are not the problem. The problem is that there are no markets for these medications in most poor countries. Things worked out in Brazil because of political will” (personal communication, June 2003). For him, “no markets” in Africa, for example, dovetails with poverty *and* with local governments’ lack of a holistic vision of public health in which the public and private sectors work in tandem: “AIDS lays bare all the inadequacies of a country’s approach to public health. We see an evolution in countries that have coordinated efforts, a strong national AIDS program, partnership with private sectors, and the country’s leader supporting intervention.”

Dr. Jones continued: “Health is not an area that the Brazilian government allowed to deteriorate anywhere near the degree of what we see in other developing countries. You had an existing structure of STD clinics and World Bank funding helped to strengthen the infrastructure.” In this rendering, Brazil’s “massive political will” to treat AIDS coincides with the country’s partnership with both international agencies and the pharmaceutical industry:

Different than in Africa, in Brazil we had a successful business with our first antiretroviral products. And we will continue to have tremendously successful businesses based on our partnership approach with the government. Brazil continues to be an example of how you can do the right thing in terms of public health, understanding the needs of both the private sector and the government and its population. The government was able to take advantage of existing realities. There was no intellectual property protection for our early products, and given Brazil’s industrial capacity, they were able to produce the drugs.

I asked Dr. Jones how the pharmaceutical industry reacted to this strategy. “We were angry,” he said. But rather than withdraw from Brazil, the company used the incident over pricing and generics to negotiate broader market access in Brazil.

The downside could have been “why bother and continue to invest in Brazil?” But anti-HIV products are not the sole bread and butter of most companies. So from a portfolio perspective, any private company balances its specific activities vis-à-vis the entirety of what it is doing. This one sector was being affected but our company had been in Brazil for a long time and we continued to be ranked as a top company there. So we had to look at it in a much broader perspective than an action taken in one product category.

By juxtaposing the arguments of both corporate actors and policymakers one can identify the logic of such a pharmaceutical form of governance. Here,

political will means novel public–private cooperation over medical technologies. Once a government designates a disease like AIDS “the country’s disease,” a therapeutic market takes shape—the state acting as both the drug purchaser and distributor. As this government addresses the needs of its population (now supposedly contained in the “country’s disease”), the financial operations of pharmaceutical companies are taken in new directions and enlarged, particularly as older lines of treatment (generic ARVs) lose their efficacy, necessitating the introduction of newer and more expensive treatments (still under patent protection) that are demanded by mobilized patients. Patienthood and civic participation thus conflate in an emerging market. Development agencies (such as the WHO, UNAIDS, and the World Bank) assist this process, which has crucial ramifications for the nature and scope of national and local public health interventions.

Magic-bullet approaches (i.e., delivery of technology regardless of health-care infrastructure) are increasingly the norm, and companies are themselves using the activist discourse that access to medicines is a matter of human rights. This pharmaceuticalization of public health has short- and long-term goals, as Dr. Jones puts it:

At what point does it get to the government that today citizens put a huge premium on access to health? And it is not just a matter of guaranteeing access to the available medications but to the new ones being developed. If you don’t have the capacity to produce this new medication, then you have to find a way to align yourself and trade with those who are doing it. With a global disease like AIDS, you must play together and not on your own.

I asked former Health Minister José Serra (an economist and now governor of the state of São Paulo) whether the state had the capacity to address other large-scale diseases pharmaceutically. “Without a doubt,” the economist said.

But the problem does not lie in government. The government ends up responding to society’s pressure, and with AIDS, the pressure was very well organized. See the case of tuberculosis. It is easier to treat than AIDS, and much cheaper. The major difficulty lies in treatment adherence. But you are unable to mobilize NGOs and society for this cause. If TB had a fifth of the kind of social mobilization AIDS has, the problem would be solved. *So it is a problem of society itself* (personal communication, June 2003).

For Cardoso, too, the management of AIDS is clear evidence that politics have moved beyond the control of parties and ideologies. “There is no superior intelligence imposing anything . . . a party, a president, an ideology. Rather there are assemblages, alliances, strategies,” he stated in the interview in 2003.

Today Brazilian society is much more open than people imagine and very mobilized. In reality, people do not live in a state of illusion as intellectuals and journalists generally think of them; they have learned to mobilize and know how to make pressure and activate those in congress with whom they have affinities.

This is also true for the pharmaceutical industry and its powerful lobby, I added. Cardoso replied,

Indeed, they also mobilize because there is a struggle going on. A bet on democracy leads to this kind of diversity. The government has to navigate amid all these pressures. It must set some specific objectives and develop directives that end amid this confusion. It cannot just be on this or that side, it must more or less pilot.

The ARV rollout was implemented across the country through an ailing universal health-care system. This specific policy was aligned with a pharmaceutically focused form of health delivery that was being articulated by the Cardoso administration. Indeed, Brazil has seen an incremental change in the concept of public health, from prevention and clinical care to community-based care and medicating—that is, *public health is increasingly decentralized and pharmaceuticalized*. As part of a policy of rationalization and decentralization of assistance, in the mid-1990s the government began to recast the costly and inefficient basic pharmacy program whereby municipalities distributed state-funded medicines to the general population (this program preexisted the ARV rollout). Provinces and municipalities were urged to develop their own epidemiologically specific treatment strategies and to administer federal and regional funds in the acquisition and dispensation of medicines. According to government officials, the policy would contribute to reducing hospitalizations (which tended to dominate state funding) and to making families and communities stronger participants in therapeutic processes (Cosendey, Bermudez, Reis, Silva, Oliveira, et al. 2000).

Overall, as I discovered in my fieldwork in the southern and northeastern regions, the availability of essential medicines has been subject to changing political winds; treatments are easily discontinued, and people have to seek more specialized services in the private health sector or, as many put it, “die waiting” in overcrowded public clinics. Even though the responsibility for distributing medicines has become increasingly decentralized, the lobbies of patient groups (modeled after AIDS treatment activism) and of the pharmaceutical industry have kept the federal government responsible for the purchase of medication classified as “exceptional,” as well as medication for disease populations that are part of “special national programs” such as the AIDS program. An increasing number of patients are filing legal suits, forcing regional governments to maintain the inflow of high-cost medicines that are

entering the market. According to public health expert Jorge Bermudez “an individualized rather than collective pharmaceutical care” is being consolidated in the country (Bermudez et al. 2000). A critical understanding of the AIDS policy’s success must keep in sight this mobilization over inclusion and exclusion as global drug markets and certain forms of “good government” are being realized.

Global Health Politics

The AIDS crisis in the developing world is finally on the radar of transnational organizations, governments, and citizens alike. Many public- and private-sector treatment initiatives are being launched, and the international debate has now shifted to how this can be most effectively done in contexts of limited resources. According to activist groups, the Global Fund to Fight AIDS, TB, and Malaria “represents the globalization of Brazil’s model of harnessing the forces of government and civil society to confront the AIDS challenge.”⁷ More than 100 countries have together committed a total of \$3 billion to the Global Fund—an international health financing institution—with the United States pledging to donate the most, \$2 billion. Here, governments and civic organizations focus on funding rather than implementation. The development of aid projects (mostly aimed at helping women and vulnerable children) is left to local groups. When the United Nations’ AIDS Program was founded in 1996 it had \$300 million available for loans to middle- and low-income countries. This budget increased to \$4.7 billion by 2003. The World Bank, which has supported the development of the Brazilian AIDS program, has played the largest role in financing UNAIDS.

This increase in AIDS funding in recent years “is largely a fruit of the well-coordinated activism of the international community,” stated Dr. Paulo Teixeira, Brazil’s former AIDS coordinator, in a Global Health Governance Workshop in São Paulo in June 2005 (see Wogart and Calcagnotto 2006). “We have changed the discourse and paradigm of intervention,” he told me. “It has become politically costly for development agencies and governments not to engage AIDS.” Yet, the operations of global AIDS programs and their interface with governments and civic organizations “reflect and extend existing power relations, and this synergy can be quite negative,” Dr. Teixeira added. “The negotiating power of developing countries is simply too low, be it at the United Nations or at the WTO. AIDS gave poorer countries a small window of opportunity to intervene in global governance and to try to recast the uneven correlation of forces.”

Dr. Paulo Teixeira is an insider to these emergent forms of transnational (pharmaceutical) governance. Alongside Dr. Jim Yong Kim, he helped coordinate

the joint WHO and UNAIDS “3 by 5” campaign, aimed at providing ARVs to 3 million people by 2005. In June 2005, the WHO reported that approximately 1 million people were on ARVs in low- and middle-income countries, in contrast to 400,000 in December 2003. Dr. Kim reflected on falling short of the desired target: “We didn’t do enough, and we began to deal with the problem too late.” Yet, “before ‘3 by 5’ there was no emphasis in saving lives,” he said. “Many world leaders thought that we had to forget this generation of HIV-infected people and to think only of the next generation. We did something to change this.”⁸ Indeed, increased availability of ARVs averted an estimated 250,000–350,000 premature deaths in the developing world in 2005 alone (WHO 2006). Yet, funding bottlenecks, personnel shortages, and continuing debates on drug pricing and patents have limited this and many other AIDS initiatives. As Dr. Teixeira put it, “In the name of their own interests, private foundations, rich governments, and pharmaceutical companies keep putting all kinds of obstacles to a more rapid scale-up of AIDS treatments. Interventions of the pharmaceutical companies are paralyzing the WHO.”

In October 2005, I talked to Dr. Jane Walker, the executive vice president of a U.S.-based pharmaceutical company. For her, the Brazilian AIDS treatment program worked “not so much because of politics, but because of a good allocation of resources.” As for treating AIDS in poorer regions, Dr. Walker insisted that “drug price is not the problem; the problem is infrastructure.” Dr. Walker was now leading her company’s efforts to “not just” bring ARVs to women and children in hard-hit places in sub-Saharan Africa, “but to build up local treatment capacity.” This medical care and research endeavor was carried out in partnership with global AIDS initiatives, local health-care groups, and NGOs. For this executive, it seemed matter-of-fact that public-private partnerships did better infrastructural work than state institutions alone. This discourse of state replacement, I thought, added an activist and morally urgent spin to a central tenet of neoclassical economics: the idea of a self-regulating market. The challenge, Dr. Walker told me, “is to find treatment models that can be inexpensively scaled up. Every one of the estimated 40 million people living with HIV is a person. We must do something as a world. We must save every one of these lives. The solution is not medicine as we practice and as we know it. We must save every one of these lives.”

In this philanthropic discourse, one saves lives by finding new technical tools and cost-effective means to deliver care: that is, medicines and testing kits. The civil and political violations that precede disease are apparently out of sight in this pharmaceutical humanitarianism, and the economic injustices reflected in barely functioning health-care systems are depoliticized (Farmer 2003). In the end, governments function on the business side, merely purchasing and distributing medicines, while nurture—now a technological endeavor—is left to communities and patients.

The U.S. president’s \$15 billion Emergency Plan for AIDS Relief (PEPFAR) reflects this global pharmaceutical frame of assistance. Announced in early 2003, PEPFAR aims to bring therapy to 2 million people and to prevent 7 million new infections by 2008 in 15 of the neediest countries in Africa and the Caribbean. However, there is a catch: rather than subscribing to the WHO’s drug-approval process, PEPFAR requires separate approval from the U.S. Food and Drug Administration (FDA). Officials claim that this is to protect the safety and quality of drugs. But critics have accused the Bush administration of delays and of actually reserving money for expensive brand-name drugs, thus reducing the number of potential recipients.⁹ Defying these and other criticisms, in May 2004 PEPFAR began buying generics, and in July 2006 the FDA approved a generic 3-in-1 combination ARV made by the Indian manufacturer Aurobindo Pharma. According to Dr. Mark R. Dybul, acting U.S. global AIDS coordinator, it is unclear if the generic drug will significantly cut costs, but by requiring patients to only take 1 pill 2 times a day the combination drug “should facilitate better therapies and better adherence.”¹⁰ Global ARV rollouts rightly open the door to drug access, but they also exemplify the inadequacies of a magic-bullet approach to health care. The methodological designs of AIDS treatment programs (pilot and otherwise), as well as the models they employ need to be carefully scrutinized by policymakers and politicized by activists. PEPFAR, for example, has an expeditionary quality, implemented from without, and is designed to save lives. It favors large-scale drug distribution but does not adequately address the issue of public health-care infrastructure improvements, or, for that matter, prophylaxis and treatment of opportunistic diseases. This focus on drug delivery and supply chain management stretches far beyond ARV rollout and has recently contributed to popularizing blanket treatment approaches for many tropical diseases, including preventive medications for conditions such as childhood malaria and river blindness, as well as antibiotic treatments that have no preventive function in national deworming campaigns for schoolchildren. Critics have rightly pointed out that, generally speaking, the strategies underlying new global health interventions are not comprehensive and are ultimately of poor quality (Epstein 2007; Ramiah and Reich 2006). Many question their sustainability in the absence of more serious involvement of national governments and greater authority for international institutions to hold donors and partners accountable. With health policy’s success largely re-framed in terms of providing and counting the best medicines and newest technology delivered, what space remains for the development of low-tech solutions (such as community development or the provision of clean water) that could prove more sustainable and ultimately more humanistic?

Drugs are ancillary to the full treatment of the disease. Alone, neither money nor drugs, or even a sophisticated pilot model guarantee success. Healing,

after all, is a multifaceted concept, and healing is no more synonymous with treatment than treatment is with drugs. Large-scale treatment programs tend to miss cultural systems and the interpersonal networks that link patients, doctors, and governments, which are especially important in resource-poor settings, where clinical infrastructures are not improving (Whyte, Whyte, Meinert, and Kyaddondo 2006). This elision of the local from the planning framework leaves unaddressed the clinical continuity necessary for successful AIDS treatment. As a result, extremely well-endowed efforts—facing the humanitarian paradox of lifesaving drugs versus caregiving infrastructure—are by and large falling short of the mark, without effecting the changes hoped for.

The work of anthropologist-physician Paul Farmer and Partners in Health provides a contrasting community-based model for AIDS treatment. The HIV Equity Initiative in Haiti does not operate like a traditional NGO, that is, removed from people. A pragmatic solidarity with the ill and destitute is its starting point. It uses the local clinic as the nexus of care within integrated prevention activities and ARV administration. “Improving clinical services can improve the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma,” states Farmer (n/d; see also Walton, Farmer, Lambert, Léandre, Koenig, et al. 2004). In this holistic approach, accounting for individual trajectories and staying with patients through the progression of the disease (the work of *accompagnateurs*) is considered as important as tackling the social factors that affect patients’ families and mitigating the decays of clinical infrastructures.

While Partners in Health’s treatment initiative is by no means accepted as a gold standard, its presence has created dents in the prevailing rationalities that guide the treatment of AIDS in resource-poor settings. In challenging the view that comprehensive care of this sort is unsustainable, the project has gained a kind of iconic role/value, expressing unforeseen possibilities and articulating a new human rights imperative. However, its expansion also begets an array of questions concerning the ethical grounds for prioritizing AIDS over other diseases of poverty (malaria and diarrhea, for example), as well as political questions regarding its operationalization and sustainability over time (Das 2006). The WHO’s difficulties in pushing forward with the “3 by 5” campaign leave no doubt that even the noblest of efforts are inherently political and must be understood in relation to the strategies of both national governments and global initiatives. Nonetheless, Partners in Health has opened up new spaces and redefined the perceived boundaries of feasibility.

Drug Resistance and the Sustainability of ARV Rollouts

In our conversation in June 2005, Dr. Teixeira expressed concern about the sustainability of Brazil’s AIDS treatment policy. “I had high hopes in this

government. But for reasons that have not been made public, the government has been reluctant to make bold moves as far as generics, patents, and international relations are concerned.” By early 2004, for example, the national AIDS program had taken the technical and legal measures that were needed for the government to issue compulsory licenses for the production of 2 patented drugs that took up almost 60% of the country’s AIDS treatment budget. “We had preliminary agreements with Indian companies to provide us the necessary chemical materials, and I was at the WHO to provide international support,” Dr. Teixeira stated. “It was just a matter of the health minister appearing on national television and announcing it, but he did not.” Other public health scholars at the Global Health Governance Workshop told me that the AIDS policy had actually lost some of its political currency, as it was taken as a “success story of the previous administration.” The current administration wants to construct “its own success stories.” As is always the case in Brazil’s political culture, electoral motives take priority over policy continuity. Besides political factors, “there is also confusion and administrative incompetence,” pointed out Michel Lotrowska, an economist working for Doctors Without Borders’ research program on neglected diseases in Rio de Janeiro. Given new budgets and bureaucracies, for the first time in 2005 there were shortages of ARVs in the health-care system, Lotrowska stated.¹¹

“The vigilance that was in place is being compromised,” Dr. Teixeira added. “We are lagging in technology.”¹² The ARV reverse engineering program at Farmanguinhos (the state’s main laboratory) has been partially dismantled and generic drug development is not keeping pace with the market. Lotrowska gave the example of Tenofovir, an important rescue drug (used in case of treatment resistance):

Brazil is one of the few emerging markets in which companies make money with ARVs. So they isolated Brazil in terms of pricing. It is a very expensive drug, it takes a lot of the AIDS budget, and there is nothing to replace it. India never got interested in producing it, and Brazil did not think prospectively. The government cannot issue a compulsory license for it. Things are disorganized, and people at various levels of government are fighting each other. The country’s machinery of AIDS drug development is stalled. Of course, all this is good for big pharma.

Brazil is now experiencing what other countries treating AIDS will soon face. It has very inexpensive first-line ARVs, but a growing number of people are going into new drug regimens (either because earlier combinations did not work or because patients and doctors are demanding access to more sophisticated drugs, with fewer side effects) that are entering the market. With patients taking advantage of new treatments, Brazil’s ARV budget has increased to nearly \$500 million in 2005. In spite of the country’s generic production, about 80% of the medication in the budget is patented. Lotrowska concluded:

We are moving toward absolute drug monopoly. In a few years, the price of AIDS treatment will increase significantly. Given patent restrictions and all the bilateral agreements that are in place, we have less and less competition regarding generics. We have to find a mechanism that can lead to price reduction without this competition. Without such a mechanism, medics will soon have to tell patients "I can only give you first-line treatment, and if you become drug resistant then you will die."

In the meantime, as I have been arguing throughout this chapter, a pharmaceutically centered model of public health is being consolidated worldwide, and medicines have become increasingly equated with health care for afflicted populations. As with other disease entities, pharmaceutical companies have operated astutely within legal and regulatory windows of opportunity in the case of AIDS, redirecting activist and political gains to their own advantage—be it as public relations gains through corporate philanthropy, as financial profits from global treatment projects, or as market expansion via developing states that have made AIDS "the country's disease" (as it is with Brazil, now a captive purchaser of ARVs).

Consider Roche's recently introduced drug, T-20 (Fuzeon, enfurvirtide). This drug is the first of a new class of drugs—called fusion inhibitors, which keep HIV particles from fusing with lymphocytes—that will undoubtedly have great impact in preventing or coping with drug resistance. In Brazil, some 1,200 patients were prescribed T-20 immediately after the drug's debut, with a yearly cost of \$20,000 per patient. "When the starting price of a drug is as T-20's, it is evident that after some time you will get a 30 to 50 percent price reduction," Lotrowska told me. "But even with this reduction, what will happen to the country's AIDS budget when thousands more will need it or want it?" While back in Salvador in June 2005, I learned that pharmaceutical representatives were training local infectious disease experts to make T-20 a first-line treatment rather than simply a rescue drug. This is a common practice, according to Bart Kroger, a Dutch medical researcher now living and working in Salvador. "These opinion-makers are extremely well paid, and they present the drug and treatment options in local congresses," he said, astounded by the global reach of medical science and ethics.

The specialists take on a 'neutral' position, generally presenting positive aspects of the drug in question but also criticizing less important aspects of the drug. They don't want to sound as if they had been bought by the company. This is important for them not to lose credibility among peers and also to keep open the possibility of working for other companies in the future.

I also heard of cases where doctors began prescribing the rescue drug Kaletra (lopinavir/ritonavir) at the time of its 2002 launch in the United States, before its registration in Brazil. These doctors referred patients to a local AIDS NGO

and to public-interest lawyers, forcing the government to provide medication not yet approved by the country's National Health Surveillance Agency. For better or worse, such developments compromise the sovereignty of the state in the fields of biological and pharmaceutical governance. In the face of pervasive pharmaceutical marketing, enmeshed with patient mobilization, regulatory incoherence thrives. And these local "medical sovereigns" are now also market operators. They mediate the introduction of new drugs in the public health-care system and, as we will in the next section, in the name of adherence and concern over drug resistance, they triage away patients who could benefit from the system's caregiving capacity, dismal as it is. Meanwhile, policymakers have to ceaselessly invent new political strategies to keep the country's pharmaceutical policy in place. In May 2007, Brazil crossed a new threshold when for the first time it broke the patent of an AIDS drug. The government stopped price negotiations with Merck over Efavirenz, which is used by 75,000 Brazilians, and decided to import a generic version from India. Officials claim that this will save the country some \$236.8 million by 2012. Activists praise this move as an important advance in the widening of access to the newest and most expensive therapies.

Local Economies of Salvation

Just as the complex Brazilian response to AIDS must be understood within the wider context of the country's democratization and the restructuring of both state and market, so too it must be seen in light of its interaction with local worlds and the subsequent refiguring of lives and values. On the ground, health programs do not work in tandem and administrative discontinuities abound. Different provinces allocate public health resources differently according to the pressure of interest groups. And the AIDS NGOs that were supposed to have taken over assistance "have long lost idealism and passion," as activist Gerson Winkler bitterly told me in September 2005 in his hometown of Porto Alegre. "They keep selecting their clientele and find all kind of ways to pretend that they are fulfilling their projects' goals." Thus, against the background of budgetary constraints, regional politics, and the "professionalization and industrialization of the nongovernmental sector" (in Winkler's words), a multitude of interpersonal networks and variations in AIDS care have emerged, creating uneven levels of quality of life for patients—the underside of the pharmaceuticalization of public health. Only a few manage to constitute themselves as patient citizens, and this brings me back to Caasah.

When I returned to Caasah in December 2001, things had changed dramatically. Caasah had been relocated to a new, state-funded building. Located

in a residential area near the famous *Igreja do Bonfim* (the church of the good end), the new facility was gated all around. With treatment regimens available, long-term residents had been asked to move out, and Caasah had been redesigned as a short-term care facility (a “house of passage,” *casa de passagem*) for ill patients and a shelter for HIV-positive orphans. The triage room had been closed, and a team of social workers and nurses now worked directly with local hospitals and admitted to Caasah the patients who “fit into the institution and its norms,” in the words of Celeste Gomes, still presiding over Caasah. Disturbingly, there was no systematic effort to actively track these patients and their treatment once they left.

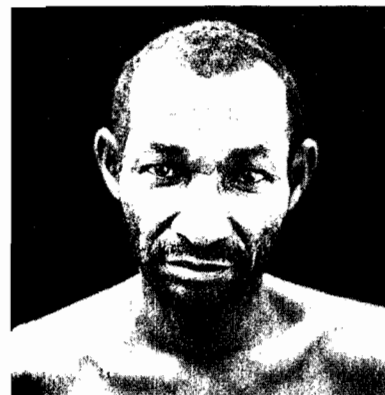
“This is a beautiful building, but that’s all the state gave us,” stated Celeste. Institutional maintenance was a daily struggle. “We owe more than \$1,000 to local pharmacies. Our patients come from the hospital with their ARVs but nothing else. No vitamins, no pain-killers, no bactrim to treat opportunistic diseases.” As AIDS became more chronic than fatal, local programs were not necessarily readjusting themselves to meet the new needs of patients. The national ARV rollout was supposed to be matched by regional government’s provision of treatments for opportunistic infections. But it was clearly up to proxy health services such as Caasah or to the patients themselves to arrange treatment beyond ARVs.

At the state hospital I learned of the existence of a triage system that Caasah is part of. “Homeless AIDS patients remain outside the system,” one of the hospital’s social worker told me. “Doctors say that they do not put these patients on ARVs for there is no guarantee that they will continue the treatment. They are concerned about the creation of viral resistance to medication.” The hospital’s leading infectious disease specialist confirmed that “if a patient is a drug user we tell him that he has to come back. If he demonstrates a strong will then we put him on treatment. But they never, or rarely, come back.” Against an expanding discourse of human rights and pharmaceutical possibilities, we are here confronted with the limits of the on-the-ground infrastructures whereby accountability and the right to envision a new life with AIDS are realized, but only on a partial basis.

I looked for my former collaborators and tracked down those who had left Caasah. Of the 22 residents I had gotten to know in-depth in 1997, 10 were alive. Only Tiquinho, the hemophiliac child who had been raised there, was allowed to stay. All of the adult survivors created new family units. They lived with other AIDS patients, reunited with estranged relatives, married, and some even had children. All of them had disability pensions and were entitled to a monthly food basket at Caasah. By charting the trajectories of these AIDS survivors—those who lived pre- and post-ARV rollout—we can identify some of the everyday mechanisms that, despite the existence of medical technology, make AIDS a chronic disease.

“Today is another world,” Luis Cardoso told me. “One Luis has died and another has emerged. A person has to think differently, forget the past.” First diagnosed with AIDS in 1993, Luis lived in Caasah from 1995 to 1999. “One Luis has died and another has emerged. I have nothing to say against the anti-retrovirals. Celeste and the psychologists motivated me a lot. But I don’t live here anymore, and I must take care of myself. I got used to the medication. Medication is me now.”

For Celeste, “Luis is like a son.” He represents Caasah and the state of Bahia in national meetings of people living with AIDS, and he runs HIV/AIDS prevention workshops in the interior. Even Dr. Nanci, Luis’ doctor, calls him “my teacher.” As she told me: “I find this fantastic. The patient had a history of self-abuse, remains poor, but rescues himself and teaches others to do the same.” Besides his AIDS disability pension, Luis also earned a salary as Caasah’s office assistant. This allowed him to rent a shack with a friend, to eat well, and to save a little, because, as he put it, “I want to have my own corner.” Open about his homosexuality, Luis insinuated he was dating. He also proudly told us that he had adopted an AIDS orphan in Caasah and was paying for the boy’s grandmother to take care of him. “The world is a school in getting lost. But it is up to me to take life forward. I always believed in God, but religious talk does not help if you don’t have the will to live inside you.”



Luis 1997



Luis 2001

(Photo by Torben Eskerod)

Luis is an amazing person, hard-working, witty, and a master of a moral discourse. He speaks of a new economy of life instincts organized around AIDS therapies. “I face my problem. I take advantage of the help I get. I struggle to live.” He is indeed the representative of a new medical collective, and his discourse conveys present-day forms and limits of society and state: “I have nothing to do with society,” he says. “From my perspective,

society is a set of masters deciding what risk is, and what is bad for them. I have never participated in that. As for the government, I must say that I am thankful for the medication. This is the good aspect of the state. The rest is for me to do.”

Luis made treatment adherence seem too easy. As much as I admired his resilience, I also found his righteousness disturbing. For him, individual conscience was the apriority of a healthy existence, and mourning a loss, any kind of loss, was a defect to be overcome. Moreover, the overemphasis on individual responsibility was self-serving. It clearly reflected Caasah's house of passage *modus operandi* and, more broadly, the predominant discourse that one has to ever more be lord of oneself, upbeat, and upward. The institutional and interpersonal forces that have thrown Luis into action in the first place were absent from his life-extending account, particularly as he spoke of noncompliant *marginais*. It was evident from his recollection that without belonging to Caasah, ARVs wouldn't have had the same kind of efficacy they had for him, and that he kept harnessing strength from being the object of regular public attention. His narrative of regeneration remains built on the exclusion of those who cannot conform:

It is not a matter of getting them [homeless AIDS patients] help. For they already have it [in the form of medication]. They use their social condition as an excuse to keep their habits. It is a question of self-destruction. As I see it, these people are more for death than for life. But I also know many people who struggle to live and to earn their money honestly and don't surrender. See Rose and Evangivaldo ... It is your mind that makes the difference.

“Welcome to the end of the world,” Rose said jokingly as I entered her brick shack, located at the lower end of a muddy hill in the outskirts of Salvador. “I am sold on the antiretrovirals,” she told me. “I am part of this multitude that will do whatever is necessary to guarantee our right to these drugs. I am proud of Brazil.” Caasah helped Rose to get the shack from the government, and she was living there with her 1-year-old daughter. She had also taken in her now teenage son who had been under the custody of Professor Carlos, Caasah's chief nurse. “I am always struggling to pay the bills and raise my children, for I am mother and father.”

Tearful, she recollected the death of her partner Jorge from AIDS-related diseases, a few months before the girl was born. She had done all that was medically possible. “Jessica got AZT, but the last exam showed that she is still seropositive.” Rose knew that the child's HIV status could change until she reached the age of 2: “She has never been ill and we hope for the best.” Rose was proud to be “a good patient, but not a fanatic one,” she added.

I drink a beer and have some fun on the weekends, but I know my limits, what my body can take. I don't live better for I lack material conditions. I tell you, I want to be alive to see a cure. In the name of Jesus, I want to be a guinea pig

when they test the vaccine. Yes, people are still dying with AIDS in the streets, but I am no longer there.

The political economy of AIDS, spanning both national and international institutions, engenders local therapeutic environments within which individuals and AIDS organizations are codependent and must recraft positions in every exchange. Their transactions are legitimated by a humanitarian and pharmaceutical discourse of lifesaving and civic empowerment. In adhering to drug regimens and making new and productive lives for themselves, patients are—in this discourse—saved. However, merely guaranteeing existence in such dire contexts, amid the dismantling of institutions of care, involves a calculus that goes well beyond numbers of pills and the timing of their intake. The political grounds of existence have been increasingly individualized and atomized, and poor AIDS patients rarely become activists. Even as they search for employment, AIDS survivors work hard to remain eligible for whatever the state's paternalistic politics and remedial programs have made available—renewal of disability benefits, free bus vouchers, and additional medication at local health posts, to name a few. Being adopted by a doctor and becoming a model patient greatly facilitates this. And this material calculus becomes all the more important as patients form new families and resume a life considered normal, which was previously impossible to them.

“What a joy you give me by coming back,” beamed 38-year-old Evangivaldo. His face was barely recognizable, but the aesthetic side effects of antiretrovirals were the least of his concerns. I met him by chance, as he came by Caasah, looking for help: “Today I woke up anguished. We had no gas to cook. I hope you can help me.” Evangivaldo and his partner Fatima left Caasah in 1999 and they had a 2-year-old daughter Juliana. “A child is what I wanted most in life. Juliana fulfilled my desire, a dream I had. I thought I would die without being a father.” He said he was on antipsychotic medication and then added: “It is the financial part of life that tortures me.” Evangivaldo showed me a piece of paper in which he had listed how his income was allocated and the debts he had to pay.

When Fatima cannot do the work, I am the man and woman of the house. Sometimes I wake up at 4 A.M., leave everything ready, and ride my bike for 2 hours, to get downtown. I go door to door, asking for a job. There are days when I cannot get the money we need and I panic. My head spins, and I fall down. I hide in a corner and cry. Then I don't know where I am. But I tell myself, ‘Focus Evangivaldo, you will find your bike and your way home.’

“And do you know why I manage to do this?” Evangivaldo asked me. “It is because my daughter is waiting for me.” Indeed, to have someone to live for and to be desired by seemed to be a core element in the account of the AIDS survivors with whom I worked.

Understanding the Nexus of AIDS, Poverty, and Politics

“If you look carefully, nothing has changed. Things are the same as you saw last time,” a tired Celeste told me in June 2005 during my last trip to Salvador. Caasah was still the only place in Salvador that provided systematic care to poor AIDS patients who have been discharged from public hospitals.

They recover here, but medication for opportunistic diseases is difficult for us to get. Some patients return to their families. Others go back to the streets. I would say that half of people living in the streets are HIV infected. The situation remains the same: disease keeps spreading, and the government pretends not to know of it, so that it does not have to intervene.

At the state’s main AIDS Unit, Dr. Nanci also told me that “things here have not changed.” As she put it: “The reality of our Unit is the same as it was in the beginning of the epidemic: full of miserable and wasted patients. The difference is that they now come from the interior, where no new services have been created. Access to therapies has been democratized, but health has not.”

I asked Celeste for news about the patients I had followed over the years. Out of the initial group of 22 patients with whom I had worked in 1997, 7 were still alive in 2005—among them, Luis, Rose, and Evangivaldo. This life extension is obviously a result of technological advancements, argued Celeste, “but it would not have happened if they had not learned to care for themselves.” In the end, treatment adherence “is relative to each person. It requires a lot of will.” Subjectivity—a person’s manufactured will to live—had become a fundamental cog in the ARV adherence machine. Yet, as I would soon learn, all of the former residents who were still alive also possessed a place they called home, a steady if meager income, and a social network. And, in case of an emergency, they could still resort to Caasah. This tie to Caasah, as momentary and uncertain as it now was, remained vital to them.

Luis was still working at Caasah. He was in charge of the institution’s fundraising activities. “I am not concerned with HIV. What I want is to live. If there is medication, let’s take life forward. Life is to fight for.” In the previous year, Luis had experienced kidney failure and had been hospitalized for 2 weeks. “Work keeps my mind occupied and one needs to have projects and objectives to meet—if not life has no meaning.” Becoming a father, he said, “is the best thing that ever happened to me.” Davi, his adopted son, was now a healthy 7-year-old—“He is a prankster. He is my passion. He makes it all worthwhile.”

“I don’t have the aid of a father and a mother, and I can only count on the tenderness of Fatima and Juliana,” Evangivaldo told me as we met again. “When I see them with no food, it makes me ill. But when I find a job or get a donation, and there is nothing lacking at home, and all is normal, then for me

it is another life, and it is all good.” I asked Evangivaldo whether he had told his doctor all he has to go through in life. “Yes,” he had once mentioned to his doctor that he routinely rode his bike for 2 hours “with only coffee and medication in the body” to get to downtown Salvador in search of a job. “Dr. Jackson said that he did not believe it, that my HIV was almost undetectable and that I acted as if I did not have AIDS. I told him that my bike was parked outside the hospital, that I would show it to him. He was amazed. He then called his superior and some residents and asked me to tell them my story.”

After the spectacle Evangivaldo had become, “The doctors said that they were proud of me, and that if all HIV-positive people had the same will to live that I have then no one would have to be hospitalized. They said that I was an example for other patients.” Evangivaldo took the opportunity to ask the doctors for advice on where to go to actually find a job, to which Dr. Jackson replied: “I feel bad for not being able to help, but I am sure that God will show a path for you to get where you want to.” Meanwhile, Evangivaldo had to take 12 pills a day, and his doctor never considered putting him on a newer medication already made available by the government (fewer pills and fewer side effects).

Poor AIDS patients such as Evangivaldo continuously interact and trade with AIDS NGOs and civic groups that channel assistance, albeit minimal, from regional and national programs. The NGOs, which depend on their clientele to back up reports and authorize new projects (now mostly related to treatment adherence and income generation), become venues for some patients to access food, rent aid, and specialized medical consultations, among other things. Overwhelmed with assistance demands and concern for their own institutional survival, NGOs rarely succeed in placing the person in the market, but they do successfully differentiate politicized patients who defend their rights from those who passively circulate in the medical service system. Only a few, such as 30-year-old Sonara, manage to become “AIDS workers.” She was Caasah’s new poster person. A nurse introduced me to Sonara—“She was a drug user, but she now takes the medication, eats well, and takes care of her daughter, who is also HIV positive”—as she was running a candle-making workshop for a group of 12 patients. Sonara was the only white person there. Her style of dress, manners, and speech were characteristic of the Brazilian middle-class. As much as I admired Sonara’s transformation, I could not have been more disturbed by her moral reasoning: “Today, people only die of AIDS if they want to.”

A recent survey on mortality in the state of São Paulo revealed that AIDS is 2 times more fatal among black patients than it is among white patients. According to researcher Luís Eduardo Batista, “The majority of blacks have less formal education, lower income and live in the peripheries.”¹³ On average, a white person in São Paulo earns almost double of what a black person earns.

From Batista's perspective, "racism impacts health" because blacks receive substandard care and go unaddressed in prevention campaigns. The violence of daily life is reinforced in this case by interlocking and discriminatory organizational contexts, which overdetermine AIDS as a medical failure. The AIDS survivors I interviewed acted coldly toward fellow patients. For many, I thought, health corresponded to a measure of moral uprightness. Mutual empathy was rare. I will never understand why, for example, Luis did not let us take Rose's food basket to her as we were heading back to her shack in the Cajazeiras district in early June 2005. The previous day, over the phone, Rose had asked me to do just that. She would save a long trip and transportation expenses, I told Luis. But my request met a series of obstacles, both external and internal: "The baskets are not ready. Professor Carlos is not here to release them. I don't have much time. I must be back no later than 11 A.M. We have to go."

Rose was euphoric to see us. She was doing great. I was particularly happy to learn that her daughter had turned HIV-negative. Ricardo, her 15-year-old son, was helping 2 workers to finish the house's second floor: "It is my skyscraper. Water was infiltrating, and in the long run I plan to rent it out." She was disappointed that we had not brought her basket. I offered Rose a ride back to Caasah, but she said that she couldn't leave the construction unattended: "That's life. Each one is on her own." Rose intelligently navigated the local circuits of AIDS care. She had garnered the support of other NGOs and opened up a little business she called "*Rose tem de tudo*" (Rose has it all), and had also devised a construction fundraising campaign among religious philanthropists. She was proud of having been able to enroll her son in project Teenage Citizen (*Adolescente Cidadão*), which Dona Conceição was running with World Bank funds.

Later that week, I met with Dona Conceição. She had accomplished much and now headed IBCM (the Conceição Macedo Assistential Institute). With the help of a local sociologist, she had designed a project to employ 120 children of AIDS patients in local industries. She kept working with homeless and poor AIDS patients. "In the morning I am at IBCM, and in the afternoon I am in the streets." Dona Conceição aided a total of 200 families, she said: "Once a month, I also hold a general meeting for these AIDS patients to share experiences. I offer breakfast and they get their food baskets." Dona Conceição regretted that she remained the only institution to address AIDS in the streets; her funds from the World Bank would only last a year: "We cannot meet all the demand for help. It's a disgrace."

Pauper patients are not the problem in themselves. With no political voice, they have been both disregarded and made invisible. This is not due to governmental inability or ignorance. Where there has been active HIV research, testing, and care—in maternity wards, for example—infection has been curtailed.

If this is ethically acceptable and technologically possible, why not tinker with the HIV testing apparatus and organize alternative forms of on-site testing, side-by-side with medical care? To ensure quality care, policymakers would need to discuss interventions with particular vulnerable groups and make adequate medical information and technology available to them, along with sustained assistance. A deliberate engagement by AIDS NGOs in local politics might break open some new ground on this front.

Conclusion

Brazil's bold, multiactor, and large-scale therapeutic response to AIDS has made history. In this chapter, I have explored the broad economic and political effects that treating AIDS had on health services, both national and local, and how this lifesaving policy influenced international efforts to reverse the pandemic's course. I have also illuminated communal and individual modes of life that have emerged around ARVs among the country's most vulnerable urban populations. In highlighting the successes, failures, and complexities of the Brazilian response to AIDS, I have revealed significant structural, logistical, and conceptual changes in governance and citizenship—groundbreaking in their own right.

The Brazilian AIDS policy is emblematic of novel forms of state action on and toward public health. Pressured by activists, the democratic government was able to negotiate with the global pharmaceutical industry, making ARVs universally available to its citizens and also opening up new market possibilities for that industry. The sustainability of the policy has to be constantly negotiated in the marketplace, and one of the unintended consequences of AIDS treatment scale-up has been the consolidation of a model of public health centered on pharmaceutical distribution. This intervention gains social and medical significance by being incorporated into infrastructures of care that are themselves being reshaped by state and market restructuring.

There has been a striking decrease in AIDS mortality in Brazil, but seen from the perspective of the urban poor, the AIDS treatment policy is not an inclusive form of care or citizenship. Many are left out, saddled with categorizations such as drug addict, prostitute, beggar, and thief. Burdened by these labels, it is difficult for individuals to self-identify or to be identified as AIDS victims deserving of treatment and capable of adherence—they largely remain part of the underground economy and a hidden AIDS epidemic. As my ethnography shows, local AIDS services triage quality treatment, and wider rights for the poor and sick to housing, employment, and security remain largely unavailable. Therapy access reveals the urgency of improving people's basic living conditions. Moreover, damaging side effects should not be

diverted to the afflicted themselves but should be guarded against by more and not less prevention-oriented policy making. Local politics matter and public institutions are indeed co-functions of successful AIDS treatment. This calls for ongoing self-examination by those who implement policies of their own effects on events and a search for ways to break open the widespread societal deafness to those most vulnerable, people who remain unheard despite all they have to say. It also involves a rethinking of how to reach the afflicted in their own terms, acknowledging self-destructiveness and human struggles for recognition in a largely hostile world. Likewise, at issue is a reconsideration of the systemic relation of pharmaceutical research, commerce, and public health care. We should think about a more sustainable solution to the obstacles posed by patentability and the pharmaceutical industry. The solution may indeed lie in comprehensive knowledge and technology sharing among southern countries already under way, a paradigm that would allow poorer countries to pool their manufacturing know-how and unite in the fight for fair prices, among other things. As Dr. Paulo Picon, a Brazilian academic scientist, told me: "If we don't find intelligent ways to counter this profit extraction from public health we will be left with insurmountable indebtedness, a wound that will not heal."

Caasah's former residents are the new people of AIDS. After experiencing social abandonment, they have come into contact with the foundational experiences of care and biotechnology. Refusing to be overpowered, they plunged into new environments. They have by all standards exceeded their destinies. Now receiving treatment, Rose, Luis, Evangivaldo, and many others refuse the condition of leftovers; they humanize technology, and redo themselves in familiar terms. And they face the daily challenge of translating medical investments into social capital and wage-earning power. They live between moments, between spaces, scavenging for resources. At every turn, they must consider the next step to be taken to guarantee survival.

Acknowledgments

In doing the research from which this chapter draws, I had generous support from the John D. and Catherine T. MacArthur Foundation, the Wenner-Gren Foundation, and the Committee on Research in the Humanities and the Social Sciences of Princeton University. I also acknowledge the support of Princeton's Grand Challenges research cooperative on Global Health and Infectious Disease. I am deeply grateful to Adriana Petryna, Tom Vogl, Amy Moran-Thomas, Alex Gertner, Marcia Inhorn, and Robert Hahn for their insightful comments and editorial help.

Notes

1. According to the World Health Organization, by early 2007 some 2 million patients in low- and middle-income countries were receiving AIDS therapies.
2. By "structural violence" I mean the way in which society's organization and institutions systematically deprive some of its citizens of basic resources and rights (Farmer 2003).
3. Caasah means Casa de Apoio e Assistência aos Portadores do Vírus HIV (House of Support and Assistance for Carriers of the HIV Virus). Caasah is pronounced like "casa," which means house in Portuguese.
4. Several studies in Brazil have uncovered a variety of factors associated with poor adherence to ARVs, and these findings have bearing on how we understand particular hardships and the possibilities for positive treatment outcomes in a place such as Caasah. See Abadia-Barrero and Castro 2006; Brigido, Rodrigues, Casseb, Oliveira, Rossetti, Menezes, et al. 2001; Nemes, Carvalho, and Souza 2004.
5. States do not necessarily weaken amid economic globalization. As states reform, they develop new strengths and novel articulations with populations (Hansen and Stepputat 2006; Ong 2006).
6. http://www.imshealth.com/ims/portal/front/articleC/0,2777,6599_3665_77491316,00.html
7. <http://www.sarid.net/health/healthdocs/050701-hiv.htm>
8. M. Morris, "OMS admite fracasso em meta de combate ao HIV," *Folha Online* 11/28/2005.
9. <http://www.avert.org/pepfar.htm>
10. *The New York Times* July 6, 2006. See also <http://www.un.org/ecosocdev/geninfo/afrec/vol19no1/191aids.htm>
11. See the report "Laboratórios apontam atraso de repasses," *Folha Online*, February 24, 2005 <http://www1.folha.uol.com.br/folha/cotidiano/ult95u106036.shtml>
12. See the report "Brazil Again Seeks to Cut Cost of AIDS Drug," *The New York Times*, August 19, 2005, <http://www.nytimes.com/2005/08/19/business/19abbott.html> See the report "Programa do Brasil para Aids 'é insustentável,'" *Folha Online*, May 31, 2006, <http://www1.folha.uol.com.br/folha/bbc/ult272u53675.shtml>
13. Mortalidade de negros é maior do que a de brancos *Folha Online* August 3, 2005 (9:44 am). See <http://www1.folha.uol.com.br/folha/cotidiano/ult95u111617.shtml> (downloaded on March 12, 2008).

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