

In the Name of Humanity

THE GOVERNMENT OF THREAT AND CARE

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"MEDICATION IS ME NOW" 

Human Values and Political Life in the Wake of Global AIDS Treatment

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Photographs courtesy of Torben Eskerod

AMID DENIAL, stigma, and inaction, AIDS became the first major epidemic of present-day globalization. By the end of 2007, an estimated 33.2 million people worldwide were living with HIV, and 9.7 million people needed antiretroviral drugs (ARVs). The number of people receiving treatment increased by about 1 million that year, and at the beginning of 2008 nearly 3 million people in low- and middle-income countries had access to antiretroviral therapy (UNAIDS/WHO/UNICEF 2008). Unprecedented alliances among AIDS activists, governments, philanthropic and international agencies, and the pharmaceutical industry have made increased access to antiretroviral therapy possible. The battle for access has been hard fought on multiple fronts worldwide, and the boundaries of feasibility have been redefined.

Many public- and private-sector initiatives are being launched today, seeking to address AIDS therapeutically in places where treatments have been scarcely available. These initiatives raise a new set of national and global health-care policy challenges regarding adequate drug delivery, sustainable treatment access, and the integration of treatment with prevention. Broader

questions arise as well: How can accountability of all sectors be assured? How do these trends affect the role of governments and their human rights obligations? Moreover, how are other deadly diseases of poverty that have less political backing being dealt with? Which value systems and policy decisions underscore medical triage? And what effects do all of these issues have on the experience of living with HIV/AIDS and poverty?

Brazil is known for its stark socioeconomic inequalities and persistent development challenges. Yet, against all odds, Brazil has invented a public way of treating AIDS (Bastos 1999; Biehl 2004; Galvão 2000; Parker, 1997). In 1996, during a time when global responses to HIV/AIDS were largely based on prevention, Brazil became the first developing country to adopt an official policy of free and universal distribution of antiretroviral drugs. Although this policy depended for implementation on an ailing public health-care system, Brazil nonetheless significantly scaled up treatment. Some two hundred thousand Brazilians are currently taking ARVs for which the government pays, and this life-saving policy is widely regarded as a model for stemming the AIDS crisis worldwide (Berkman et al. 2005; Okie 2006).

In a time when global health mandates are largely tagged to top-down diplomacy or corporate citizenship, I took it as my task to illuminate the intricacies of this off-center public health solution and to explore its reach (Biehl 2007). Throughout this chapter, I consider the political and economic factors underlying this therapeutic policy and identify the novel power arrangements (both global and national) that are crystallized in Brazil's response to AIDS. As I probe the AIDS policy's social and medical reach, particularly in impoverished urban settings where AIDS is spreading most rapidly, I also inquire into the micropolitics and desires that invest ARVs and make survival possible. Brazil's response to AIDS thus provides us with a unique opportunity both to apprehend shifting public-private involvements in a neoliberal landscape and to assess their immediate and long-term effects.

I draw from open-ended interviews I carried out with activists, policy makers, health professionals, and corporate actors in Brazil and the United States between 2000 and 2006. 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 state of Bahia (1995–2005). Moving back and forth in space and time, ethnographic fieldwork allows us to see these various actors and forces in operation, reminding us that there is no short cut

to understanding the multiplicities of reality and practice through which a technologically extended life is achieved.

How has the AIDS policy become a kind of public good, emblematic of the state's universal reach, even though it affects only a small fraction of the citizenry? What networks of care emerge around the distribution of lifesaving drugs? How do the poorest citizens understand and negotiate medical services? How are individual subjectivities and ideas of care both of the self and of others recast in relation to broader economic, political, and medical transformations? What do these struggles over drug access and survival say about government, human values, and ideas of the future?

Longitudinal ethnographic work remains, in my view, a vital social scientific antidote to what the economist Albert O. Hirschman (1970) identifies as "compulsive and mindless theorizing." As he writes, "quick theoretical fix has taken its place in our culture alongside the quick technical fix" (329). For Hirschman as for the ethnographer, people come first. This respect for people, this attention to the manufacturing of clinical and political discourses and to the sheer materiality of life's necessities makes a great deal of difference in the knowledge we produce. Large-scale processes are not abstract machines overdetermining the whole social field. Social mobilization and personal actions, for example, have made a world of difference in expanding treatment to the poorest people afflicted by AIDS (Farmer 2004; Helen Epstein 2007). The microarrangements of individual and collective existence cannot be solely described in terms of power, either. Overconfidence in power arrangements and rational choice is itself a cultural product to be scrutinized. As Hirschman (1970: 338) writes, "In all these matters I would suggest a little more reverence for life, a little less straitjacketing of the future, a little more allowance for the unexpected—and a little less wishful thinking."

THE POPULATION/PEOPLE CAESURA

Michel Foucault has argued that beginning in the eighteenth century the "naturalness" of population became central to Western techniques and conducts of government. The notion of population worked as a frame for addressing the economic and political problems of food scarcity, epidemics, and the circulation of goods and people in newly urbanized spaces.

Rather than focusing on individual juridical subjects, government became increasingly concerned with the management of things: “Things are men in their relationships with things like customs, habits, ways of acting and thinking . . . with things like accidents, misfortunes, famine, epidemics, and death” (Foucault 2007: 96). This governmental management (or political economy) triangulates with sovereignty and discipline, and it has “population as its main target and apparatuses of security as its essential mechanism” (108). Man becomes to population what the subject of rights was to the sovereign (79).

I find this analytics helpful, to a point. For Foucault, the notion of the population-subject as the primary object of security is marked by a fundamental caesura between what is pertinent and what is not for the government’s economic and political action. “The multiplicity of individuals is no longer pertinent, the population is” (42). The people comprise those who conduct themselves “as if they were not part of the population as a collective subject-object, as if they put themselves out of it, and consequently the people are those who, refusing to be the population, disrupt the system” (44). What happens to the population/people caesura under neoliberal governmental reforms? When and under what conditions does people’s inclusion or exclusion from the governmental radar stop being a security concern?

For Foucault, governmentality is “both external and internal to the state, since it is the tactics of government that allow the continual definition of what should or should not fall within the state’s domain, what is public and private, what is and is not within the state’s competence, and so on. So, if you like, the survival and limits of the state should be understood on the basis of the general tactics of governmentality” (109; see also Ferguson and Gupta 2002). I am interested in the arts of government that accompany economic globalization and the remaking of people as market segments (specifically, therapeutic markets). How do patient-citizen-consumers draw from government and it make it resourceful as they negotiate the vagaries of the market and economic survival? How are the poorest people part of government and which idioms of “humanity” make them visible? How do people triage each other in the day-to-day?

The ethnographer upholds the rights of a microanalysis and thus brings into view the immanent fields—leaking out on all sides—that people invent to live in and by. Gilles Deleuze’s conceptual work is particularly relevant

here. He does not share Foucault's overconfidence in power arrangements, and he is particularly concerned with the borders between the macro and the micro: "A society, a social field does not contradict itself, but first and foremost, it leaks out on all sides. The first thing it does is escape in all directions. Far from being outside the social field or coming from it, flight lines constitute its rhizome or cartography" (Deleuze 2006: 127). Such immanent fields of action are mediated by governmental techniques, yet they are also animated by claims to basic rights and "assemblages of desire" (126). In bringing into public view these localized and multidimensional fields of engagement and possibilities, always on the verge of being sealed off or foreclosed, the ethnographer still allows for some general principles to surface (or to become irrelevant).

Yes, global markets are incorporated via medical commodities, and my ethnography shows that medicines have become key elements in the state's arsenal of action. Yet, while new pharmaceutical markets have opened, and AIDS therapies have been made universally available (the state is present through the dispensation of drugs), it is up to individuals and communities to take on locally the roles of medical and political institutions. This pharmaceuticalization of governance and citizenship, obviously efficacious in the treatment of AIDS, nonetheless crystallizes new inequalities. This medical intervention—funded and organized by the state alongside international institutions and produced by the pharmaceutical industry—has resulted in effective treatment for working-class and middle-class Brazilians, meanwhile leaving the marginalized underclass by the wayside. These individuals cope by using survival strategies that require extraordinary effort and self-transformation.

AIDS therapies are now embedded in landscapes of misery, and hundreds of grassroots medico-pastoral services have helped make AIDS a chronic disease also among the poorest. This is not a top-down biopolitical form of control. The government is not using AIDS therapies and grassroots services as "techniques . . . to govern populations and manage individual bodies" (as the anthropologist Vinh-Kim Nguyen [2005: 126] has framed the politics of antiretroviral globalism). Throughout this chapter, I show that the question of accountability has been displaced from government institutions, and poor AIDS populations take shape, if temporarily, through particular engagements with what is made pharmaceutically available. The political game here is one of self-identification. Proxy communities, often

temporary and fragile, and minor knowledges and desires are fundamental to life chances, unfolding in tandem with a state that is pharmaceutically present (via markets) but by and large institutionally absent.

At the margins, both the institutional and pharmacological matters surrounding AIDS treatment undergo considerable flux. Poor AIDS survivors themselves live in a state of flux, simultaneously acknowledging and disguising their condition while they participate in local economies of salvation and articulate public singularities. Against the backdrop of a limited health-care infrastructure and economic death and through multiple circuits of care, individual subjectivity is refigured as a *will to live*. Far from being the representative of a natural vitality, this will to live is constantly fought for, asserted, and renegotiated in the marketplace by those with the means to do so, limited as those means may be. At both the macro and micro levels, we see a state of triage and a politics of survival crystallizing.

Ethnography's unique theoretical force lies in recording competing rationalities and vital experimentations, in challenging orthodoxies of all kinds and conceptualizing fine articulations of worlds—differentiated, in flux, and impending (Fischer 2009; Rabinow 2008). Moreover, grasping social fields and subjectivity as becoming—rather than as determination—may be the key to anticipating, and thereby making available for assessment and transformation, the futures and forms of life of emerging communities. Thus, continually adjusting itself to the reality of contemporary lives and worlds, the anthropological venture has the potential of art: to invoke neglected human possibilities and to expand the limits of understanding and imagination. “There is no work of art,” writes Deleuze (2006: 324), “that does not call on a people who does not yet exist.”

THE HUMAN RIGHT TO HEALTH

Brazil is the epicenter of the HIV/AIDS epidemic in South America and accounts for more than 50 percent 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 (Castilho and Chequer 1997; Berkman et al. 2005). At the end of 2001,

an estimated 610,000 Brazilians were living with HIV/AIDS (an adult prevalence of 0.7 percent, 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. Since 1998 the death rate from AIDS has steadily declined, an achievement attributed to the country's treatment policy (Dourado et al. 2006).

Throughout the 1990s, different sectors—gay groups, AIDS nongovernmental organizations (NGOs), grassroots services, and central and regional governments, along with the World Bank—came together, helping to address what was earlier perceived to be a hopeless situation (Bastos 1999; Parker 1994, 1997). Activists and progressive health professionals migrated into state institutions and participated in policy making. 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 the manufacturers 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 treatment universally available. Article 196 of the democratic constitution adopted in 1988 affirms health as a right of the people and a duty of the state—and AIDS activists were the first group to equate this right effectively to therapy access.

The Brazilian government was able to reduce treatment costs by reverse engineering antiretroviral drugs and promoting the production of generics in both public- and private-sector laboratories (Cassier and Correia 2003). Had a generics infrastructure 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 firms by threatening to issue compulsory licenses for patented drugs. Media campaigns generated 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. According to the Health Ministry, both AIDS mortality and the use of AIDS-related hospital services have fallen by 70 percent. Brazil's treatment rollout has become an inspiration for international activism and a challenge for the governments of other

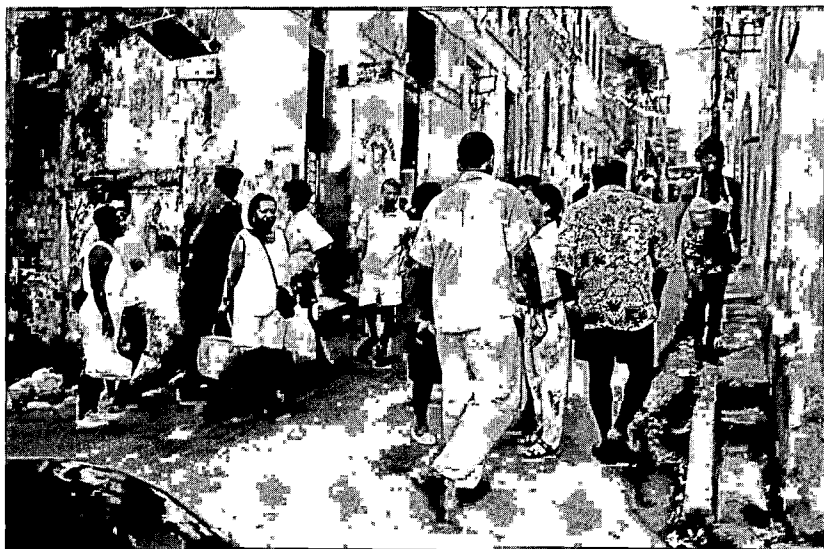
poor countries devastated by the AIDS pandemic. This policy challenged the perception that treating AIDS in resource-poor settings was economically unfeasible, and it showed how lifesaving drugs could be integrated into public policy even in the absence of an optimal health infrastructure.

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 a leadership role in the AIDS program of the World Health Organization (WHO), and it is supporting international networks aimed at facilitating treatment access and technological cooperation on HIV/AIDS. In recent 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 vulnerability to disease.

PERSISTENT INEQUALITIES AND CIRCUITS OF CARE

I was in the coastal city of Salvador da Bahia conducting fieldwork when AIDS therapies began to be widely available in early 1997. Considered by many “the African heart of Brazil,” Salvador was the country’s capital until 1763. A center of international tourism, Salvador today has an estimated population of 2.5 million, with more than 40 percent 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 Northeast region, ostensibly in line with the country’s successful control policy. But the AIDS reality one saw in the streets of Salvador contradicted this profile. A large number of AIDS sufferers remained epidemiologically and medically unaccounted for, dying in abandonment (Biehl 2005b). Meanwhile, community-run initiatives provided limited care for some of the poorest and the sickest.

The photographer Torben Eskerod joined me in chronicling the social work of Dona Conceição Macedo and her religious friends (see fig. 1). They provided free meals and some care to dozens of poor people and their families living with AIDS and very little else in the corners of the city’s cultural



1 Dona Conceição's charity work among homeless AIDS patients in the Pelourinho neighborhood.

heritage center known as the Pelourinho ("Pillory"). 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."

I talked to the group on several occasions. Soft-spoken, Jorge Araújo said that he learned he had AIDS after his left leg was amputated because of infections related to intravenous drug use (fig. 2). Jorge had lived by himself on the streets since the age of fourteen. At some point, he lived with an older woman and had a child, but he eventually left them. "If I kept thinking about AIDS," he told me, "I would already be dead. One must forget. . . . To be a patient one needs things. But what is there to have here?"

One should not expect these patients to adhere to medical treatments, says Dona Conceição, because "they just use medication until they recover. . . . If they don't have a home, no treatment will work." Dona Conceição did not blame her street patients. Rather, she saw their condition as a social symptom and made it into a public affair. But she also refused to treat them as a collective, and that is what drew them to her. She helped them become singular individuals, literally struggling in their place: "Each one has a history, a life left behind. Jorge suffers with all the discrimination



2 Jorge, a few years after our initial conversation, still living on the streets.

he faces. He keeps using drugs, and he is unable to overcome his personal failures. He does not struggle for health; I struggle for him.”

Jorge praised Dona Conceição, saying that she played a crucial role in the circuitry—begging, work-for-food, petty robberies, and AIDS charity—that he and his friends engaged in to survive. He had bitter words for the little help he was getting from Caasah, Bahia’s only *casa de apoio* (house of support), a grassroots house of support that he had helped to create and where I was carrying out the bulk of my ethnographic research.¹ “I still go there to get my monthly food basket. It is very little, and I still have to pay the bus ticket and split half with the colleague who carries it for me. I don’t know where all the money they get from the government goes.” Jorge also spoke, however, of a sense of belonging that took shape among street patients, eliciting a new constellation in which inner life was reframed and economic death endured: “People here are my friends. Of course, nobody will do anything for others for free. But they talk to me. They make me laugh. This gives me a bit of extra life.”

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?



3 Caasah.

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 among them) squatted in an abandoned hospital formerly run by the Red Cross (see fig. 3). "Caasah had no government," recalled the director, Celeste Gomes. "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 an 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 divisions, buttressed by strategic exchanges with hospitals and AIDS NGOs. Throughout the country, other "houses of support" like Caasah negotiate the relationship between AIDS patients and the haphazard, limited public health-care infrastructure. By 2000 at least one hundred of the country's five hundred registered AIDS NGOs were houses of support. In order 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 eighty 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."

With a simple chair and a black cloth against a wall, we improvised a photo studio outside Caasah's main building. Torben photographed each person and I recorded his or her life story.

Rose's left hand was atrophied, and she limped (fig. 4). "It is all from drug use. I was crazy." 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 of the state of Bahia and was expelled from home at the age of thirteen, after she became pregnant. She moved into Pelourinho's red-light district. By the end of 1993, Rose learned that she was both pregnant and HIV-positive. One by one, Rose gave up her children for adoption. "What else could I have done?" she said. "I couldn't give them a home. I also thought that I would not live much longer." But Rose has lived longer than she expected. She had quit drugs and remained asymptomatic. She had become literate, learned to make handicrafts, and was beginning to take AIDS therapies: "I take life in here as if it were a family, the family I did not have."

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



4 Rose, 1997.

environment that is necessary to accumulate health (see Abadia-Barrero and Castro 2006; Brigido et al. 2001; and Nemes, Carvalho, and Souza 2004). Here people did not have to worry about the stigma that came with having AIDS “on the outside,” and a scheduled routine and an infrastructure made it easier to integrate drug regimens into everyday life. An intense process of individuation—“salvation from my previous life,” as one resident 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?” Evangivaldo asked me as he had been quarantined because of his scabies (fig. 5). Residents constantly pointed to each other’s faults and demanded everyone’s adherence to the house rules. The other’s misbehavior was also a measure of their own progress, a measure of their own change and self-control: “I am not like him”; “She did it to herself, and now she wants another chance.” Money was at stake. Caasah’s administrators facilitated application for AIDS disability pensions, and priority was given to residents who showed change. Well-behaved and compliant patients were also allowed to help in the storage room, where they were given priority in choosing clothing for themselves and for family members living outside.



5 Evangivaldo, 1997.

PHARMACEUTICALS AND SELF-GOVERNANCE

In grassroots units such as Caasah, marginalized citizens have an unprecedented opportunity to claim a new identity around their diseased and politicized biology, with the support of international and national, public and private funds. Here immediate access to AIDS therapies and the administration of health—the micropolitics of survival—takes priority over “metasocial guarantees of social order” or over political representation (Doimo 1995; Abélès 2006; Holston 2008). For the moment, let us think of Caasah as a “biocommunity” in which a select group of poor patients fights the systematic denial of social rights and carves out the means to access them empirically. This political subjectivity is articulated through pastoral means, disciplinary practices of self-care, and monitored pharmaceutical treatment. At work are new arts of self-governance and survival as a cost-effective patient.

Caasah’s life-extending work challenges Hannah Arendt’s rigid view of an opposition between the realm of the political and the realm of private life. For Arendt (1958: 320–25), the modern political process has progressively eliminated the possibility of human fulfillment in the public sphere,

excluding the masses and reducing each human being in them to the condition of *animal laborans*, a creature whose only activity is biological self-preservation. This self-preservation is an individual concern, a metabolism 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" (Arendt 1973 [1951]: 302). That is, for Arendt, the primacy of natural life in modern society has foreclosed the possibility of authentic political action. Unfortunately, according to the late Iris Young, "Arendt criticized efforts to improve social life and to promote social and economic rights in the same category as the merely biological. She thought that concern for social and economic equality and inclusion was not appropriate in the public sphere" (personal communication, March 2004).

The philosopher Jacques Rancière (2004b: 299) is also concerned with the overturning of Arendt's "archipolitical position" into a "depoliticizing approach": "Paradoxically this position did provide a frame of description and a line of argumentation that later would prove quite effective for depoliticizing matters of power and repression and setting them in a sphere of exceptionality that is no longer political, in an anthropological sphere of sacrality situated beyond the realm of political dissensus." This overturn, for Rancière, is clearly illustrated by Giorgio Agamben's theorization of biopolitics in *Homo Sacer* (1998). Following Arendt and Michel Foucault (1980), Agamben (1998: 24) states that the original element of sovereign power in Western democracies is "not simple natural life, but life exposed to death." This "bare life" appears in Agamben as a kind of historical and ontological destiny, "something presupposed as nonrelational" (109). Rancière (2004b: 302) gets straight to the point: "The radical suspension of politics in the exception of bare life is the ultimate consequence of Arendt's archipolitical position, of her attempt to preserve the political from the contamination of private, social, apolitical life. This attempt depopulates the political stage by sweeping aside its always-ambiguous actors."

Caasah's residents reframe the question of what politics is. They engage government via the AIDS policy and, in the process, are able to become a local body of citizens. The universal availability of lifesaving drugs does not reshape the bureaucratic apparatuses of the state, nor does it substantially alter the medical establishment. Novel strategies for biosocial inclusion and exclusion are rather consolidated under perennial structural violence. Many

stay outside, on their own. Caasah's distinctive feature is its selective transformation of a diseased biology, marginal and excluded, into a technical means of inclusion. Scavenging for resources and navigating through complex treatment regimes, residents constitute themselves as patient-citizens.

It is within this interrelated context of local, national, and international forces that I became interested in how the project to extend life informed institutions and political agency, particularly at the margins. Here, life extension and social death are the poles of a continuum. The distribution and consumption of pharmaceuticals are significant means through which state, community, and citizen empirically forge their presence today. Nongovernmental, pastoral, and clinical networks link the worlds of marginality and the state through AIDS response.

In order to make these new medical technologies work, people have to participate actively in local circuits of care. In contexts of unemployment and scarcity, for many disenfranchised patients, the mere extension of life is literally a form of work (Petryna 2002). Thus, the deployment of AIDS therapies instantiates new capacities, refigures value systems, and alters people's sense of their bodies and of the future. The pressing needs of newly circumscribed patient populations for physical and economic survival dynamically inform private and public involvements; and these "affective entanglements," in turn, redefine the local terms of politics and ethics.

We can only understand the conflicting social effects of neoliberalism and governmental decentralization by looking at the materiality of policies and related individual and communal struggles for survival. By ethnographically charting the ways policies and people operate at the margins, we can also illuminate political rationality in the making. Politics here is not a sphere, but a lack, a technology, and a process all at once. In the case of the AIDS policy, medication makes people equivalent—difference lies in laboratory testing and viral loads. It is up to grassroots work to address the social determinants of patients' conditions or to make these markers invisible. Here medical commodities work in tandem with other ways of claiming citizenship, and desperate and creative interactions occasion novel public sites in which rights are group-privatized, so to speak.

Life in Caasah draws on what is available. Individuals do not operate alone. Their decision making and actions are entangled with those of other patients and the multiple arts of government at hand for this group. Con-

temporary conditions are pressing, and disjunctions abound. Channels of communication with people and institutions are constantly renegotiated, and newly found personal identifications cannot be taken for granted.

MARKET POLITICS

"The success of the Brazilian AIDS policy is a consequence of the activism of affected communities, health professionals, and government," Paulo Teixeira, former national AIDS coordinator, told me in June 2005. I heard a similar explanation from Fernando Henrique Cardoso, Brazil's former president, two years earlier. "Brazil's response to AIDS is a microcosm of a new state-society partnership. . . . 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."

I met with Cardoso at the Institute for Advanced Study, where he was participating in a meeting of the board of trustees. He had no qualms about extrapolating, using the AIDS 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, with a universal reach (Cardoso 1998). "Government and social movement practically fused," he told me. "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. "This new phase of capitalism," Cardoso argued, "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 of the Workers' Party (Partido dos Trabalhadores [PT]), "in the end say the same thing." That is, "that globalization is asymmetric" and that "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 control financing mechanisms." He made the case that Lula's government was basically following the same "ultraorthodox" 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.” 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 (Ong 2006).

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. One of my central arguments is that behind the concept of 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 gave 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 et al. 2000).

"Brazil bet a lot on the WTO and dove into it, body and soul," former Health Minister José Serra (an economist and now governor of the state of São Paulo) told me in an interview in 2003. "Neoliberalization developed abruptly. From a closed and protected economy we went to the opposite. This openness was unilateral. It was not a negotiating process through which the country gained something in return." As a policy maker, Serra was painfully aware of the loss of room for maneuver. "Brazil also dove into the free flow of capital. Dependence on this free flow to insure the growth of the economy can provoke a generalized instability; and this, combined with external vulnerability, can be volatile indeed. So our government was conditioned by this. And even though there was no direct pressure for privatization, nonetheless the external environment favored it. If you need an aid or credit from the World Bank, conditions are always embedded."

Serra also suggested that the mid-1990s was a transition period that left little time to critically reflect on the broader implications of the terms of economic readjustment—"things were not so clear." The long-term effects of TRIPS did not generate a great deal of public debate, for example, other than recognition that signing the treaty marked countries' conformity to global trade reforms. In particular, there was a lack of discussion about the impact of pharmaceutical patents on drug prices and accessibility. The president and his team took hasty and legally binding decisions. And from this new landscape defined by globalization, government was built. "We did not hesitate to abolish all taxes for the import of medication," Serra recalls. "Many in the national industrial sector complained, but we did this to hold the impact of exchange rates on inflation and to increase competition, to stimulate the production of generics."

Like Cardoso, Serra also denied a causal relationship between globalization and state reform. He was unapologetic about privatization, saying that "shrinking the size of the state does not mean less participation." Both politicians spoke of privatization as a means to make the state more agile so that it might both fulfill its market-regulating role and attend better to society. With the country's economy under siege, these politicians must insist that Brazil is not subservient; clearly, some form of independence and inventiveness is exercised in public policy—and that is what happened with AIDS, as it became technologically manageable.

In 1999 Serra championed the entrance of generics into the Brazilian market and gave incentives for their local production in public and private

laboratories. "Reverse engineering and the production of generics was the only way of keeping the lifesaving policy going," he said. For Serra, besides strong social pressure, the AIDS policy "basically worked because it was within the structure of the government and, in fact, because it revitalized part of the governmental structure. You find AIDS programs in every corner of the country, and, generally, they are government funded." In these novel sites, the new relationship between government and society takes form: "I was also always trying to establish new mechanisms of cooperation between government and society, working with a whole array of philanthropic organizations. To deepen the idea that the public is not just the governmental." One could also argue that local communities increasingly compensated for the state's current lack of administrative capacity, particularly as far as public health-care infrastructure is concerned.

In their pragmatic approach to globalization, both Cardoso and Serra articulate a market concept of society. Citizens are consumers who have "interests" rather than "needs." In Serra's words, "The government ends up responding to society's pressure. If tuberculosis had a fifth of the kind of social mobilization AIDS has, the problem would be solved. So it is a problem of society itself." Here, the government does not actively search out particular problems or areas of need to attend to—that is the work of mobilized interest groups. These public actions are seen as "wider and more efficacious than state action," as Cardoso put it. Moreover, the afflicted have to engage with lawmaking and jurisprudence even to be seen by the state, and the implementation of progressive laws remains subject to a whole range of exclusionary dynamics linked to economics and specific social pressure. Meanwhile, grassroots groups address the paradox that ARVs are available but public institutions are barely working. Care has been outsourced to the groups. "Did bad things happen in the process?" asked Teixeira. "Yes, but without outsourcing there would not have been advances either. Evolution is never unidirectional—it is forward and backward. We hope that it is two steps forward and one backward."

At any rate, these various practices—a technological reaffirmation of the universal public health-care system, state production, and the outsourcing of care—materialized into a new politics of pricing as Brazil threatened to issue compulsory licenses on patented drugs in order to guarantee the sustainability of the policy. In spite of the national production of generics, prices of patented drugs were seriously jeopardizing the sustainability

of the ARV rollout. Serra and national AIDS officers decided to bring the treatment question to the WTO meeting scheduled for November 2001 in Doha, Qatar. By then, there was growing international support for the Brazilian initiative, with endorsements from AIDS activist networks and UNAIDS, and editorial backing from media including the *New York Times*. Furthermore, the U.S. government was in a weaker negotiating position after it had threatened to break Bayer's patent of Cipro, seeking cheap supplies in the wake of the 2001 anthrax scare. With the support of key diplomats and NGOs, the Brazilian delegation articulated the position of a southern bloc that drafted a declaration that, at least symbolically, recaptured a developing country's sovereign right to operate outside the bounds of TRIPS for the purpose of public health—that is, in case of a crisis, countries were allowed to issue compulsory licenses for patented drugs.

In Teixeira's words: "We had to focus at every moment on the empirical steps that had to be taken to make things work, and also to maintain a temporal perspective, that is, to see things unfolding over time. The AIDS policy is a process." In practice, Serra stated, "the AIDS policy ended up working as a kind of counterweight to the economic orthodoxy in place internationally." It is through this specific constellation—the AIDS policy—that globalization assumes concrete form and meaning for some segments of the Brazilian public today. Flows of money, knowledge, and technology—mediated by international financial institutions, NGOs, trade-related treaties, lawmaking, reverse engineering, and a new state capacity—constituted a strategic terrain for novel social and political articulations which, in turn, recast AIDS and its treatment.

I am reminded here of Georges Canguilhem's (1998: 318) discussion of the "decline of the idea of progress" and his call for an analytics of "motion": "continuous progress is a conservative epistemological concept. Predictions of progress turn today into tomorrow. But it is only when tomorrow comes that we can speak of yesterday." The cumulative experience of the "unpredictability of the political and social effects of technological inventions," argues Canguilhem, are also epistemological breaks. The AIDS policy, one can say, both illuminates past political decisions and economic maneuvers—principles of inequality—and gives evidence of how these "origins" can be somewhat remediated by specific state-medical-market initiatives which, in turn, crystallize a bioeconomic or pharmaceutical form of governance.

THE PHARMACEUTICALIZATION OF PUBLIC HEALTH

The global sales of pharmaceuticals were estimated to reach \$745 billion in 2008. According a report from IMS Health, one of the world's leading market intelligence firms, "as growth in mature markets moderates, industry attention is shifting to smaller, developing markets that are performing exceptionally well."² This is the case of Brazil, now the eleventh-largest pharmaceutical market in the world. Currently, some 550 pharmaceutical firms (including laboratories, importers, and distributors) operate in Brazil and compete for a slice of this lucrative market, which in 2005 reached \$10 billion in sales. By 2010 the developing world is expected to account for approximately 26 percent of the world pharmaceutical market in value, compared with 14.5 percent in 1999.

"Pharmaceutical companies had already recouped their research investment with the sell-off of AIDS drugs in the United States and Europe," a Brazilian infectious disease specialist and adviser to the WHO explained to me, "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." John Jones (a pseudonym), an executive with 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." For him, "no markets" in Africa, for example, dovetails with poverty and with local governments' lack of a holistic vision of the public 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."

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 [sexually transmitted disease] 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.

In fact, the AIDS treatment 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, now understood less as prevention and medical attention and more as access to medicines and community-outsourced care—that is, public health is increasingly decentralized and pharmaceuticalized. In the mid-1990s, as part of a policy of rationalization and decentralization of assistance, the government began to recast the costly and inefficient basic pharmacy program whereby municipalities distributed state-funded medicines to the general population (this program predated the ARV rollout). States 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 basic medication. 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 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 has 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 the 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 pharmaceutical markets and certain forms of “good government” are being realized.

By juxtaposing the arguments of both corporate actors and policy makers, one can identify the logic of such a pharmaceutical form of governance. Here “political will” means favoring novel public-private cooperation over medical technologies. Once a government designates a disease like AIDS “the country’s disease,” a therapeutic market takes shape, with the state acting as both the drug purchaser and distributor. As the government addresses the needs of its population (now unequally refracted through the “country’s disease”), the financial operations of the pharmaceutical industry 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 coalesce in an emerging market. Moreover, companies use drug-pricing and drug-donation programs to negotiate with governments for broader market access and to expand their clinical research enterprise.

Internationally, Brazil has become proof that the badly needed full-scale assault on AIDS is indeed possible. “We have changed the discourse and paradigm of intervention,” said Teixeira, who helped coordinate the joint WHO and UNAIDS “3 by 5” campaign. “It has become politically costly for development agencies and governments not to engage AIDS.” Yet, he added, 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. The negotiating power of developing countries is simply too little, be it at the United Nations or at the World Trade Organization.” According to Teixeira, funding bottlenecks, personnel shortages, and continuing debates over drug pricing and patents have limited global AIDS initiatives. “Drug companies are paralyzing the WHO.”

Magic-bullet approaches (i.e., the delivery of technology regardless of

health-care infrastructure) are increasingly the norm in global health, and drug companies themselves are using the activist discourse that accessing therapies is a matter of human rights. This pharmaceuticalization of public health has short- and long-term goals. "It is a matter of guaranteeing access not just to the available drugs but to the new ones being developed," Jones said. "You have to find a way to align yourself and trade with the companies who are doing this work." Tellingly, one corporate social responsibility executive of a major pharmaceutical firm recently told me, "As a global health company, we are proud that about 750,000 AIDS patients in the developing world are on our drugs."

This focus on drug delivery and supply-chain management stretches far beyond the ARV rollout and has recently contributed to the popularity of blanket treatment approaches for many tropical diseases, including preventative medications for conditions such as childhood malaria and river blindness, as well as antibiotic treatments that have no preventative value in national deworming campaigns for schoolchildren. Such interventions seem to systematically ignore chronic illnesses and the complex environmental issues most central in people's lives. In the end, governments are business partners, while communities and patients are left to nurture themselves (as I chronicled in Brazil). Critics have rightly pointed out that, generally speaking, the strategies underlying new global health interventions are not comprehensive and ultimately of poor quality (Farmer 2004; Ramiah and Reich 2006; Whyte et al. 2006).³ Many question the programs' sustainability in the absence of more serious involvement by national governments and greater authority for international institutions to hold donors and partners accountable. With a health policy's success largely reframed in terms of providing and counting the best medicines and newest technology delivered, what space remains for the development of low-tech or non-tech solutions (such as community development or the provision of clean water) that could prove more sustainable and ultimately more humane?

INTERMEDIARY POWER FORMATIONS

In our conversation in June 2005, Teixeira expressed concern about the sustainability of Brazil's AIDS treatment policy. "I had high hopes for the PT [Workers' Party] government. But the government has been reluctant to make bold moves as far as generics, patents, and international relations are

concerned." Several activists told me that the AIDS policy had lost some of its political currency as it was taken as a "success story of the previous administration" (see Wogart and Calcagnotto 2006). The Lula administration wants to construct "its own success stories." With the effort under new budgets and bureaucracies, for the first time in 2005 there were shortages of ARVs in the health-care system (see Leite 2005).

"The preparedness that was in place is being compromised," Teixeira added. "We are lagging in technology" (see Prado 2005). The ARV reverse-engineering program at Farmanguinhos (the state's main pharmaceutical laboratory) has been partially dismantled, and generic drug development is not keeping pace with the market.

Brazil is facing a complex predicament that other developing countries treating AIDS will soon face. It has a very inexpensive first line of ARVs, but a growing number of people are starting new, more expensive drug regimens, either because of drug resistance or because newer drugs have fewer side effects. With patients taking advantage of these new treatments, Brazil's annual ARV budget increased to nearly \$500 million in 2005. In spite of the country's generic production capacity, about 80 percent of the medication included in the national budget is patented. "We are moving toward absolute drug monopoly," Michel Lotrowska, an economist working for Doctors without Borders (*Médecins sans Frontières*) in Rio de Janeiro, told me. "We have to find a new way to reduce drug prices. If not medics will soon have to tell patients, 'I can only give you first-line treatment, and if you become drug-resistant you will die.'"

Consider Roche's recently introduced drug T-20 (Fuzeon). 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 managing drug resistance. In Brazil some twelve hundred 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 [high as] T-20's," Lotrowska told me, "it is evident that after some time you will get a 30 to 50 percent price reduction. But even with this reduction, what will happen to the country's AIDS budget when thousands more need it or want it?"

While doing fieldwork in Salvador in June 2005, I learned that medical opinion-makers were urging local doctors to make T-20 a first-line treatment rather than simply a rescue drug. I also heard of cases where doctors

began prescribing the rescue drug Kaletra 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 who pressured the state to provide drugs not yet approved by the National Health Surveillance Agency (Agência Nacional de Vigilância Sanitária, or ANVISA). In the face of pervasive pharmaceutical marketing enmeshed with patient mobilization, regulatory incoherence thrives. Meanwhile, activist policy makers have to ceaselessly invent new political strategies to keep the country's AIDS treatment rollout in place. The pharmaceutical industry is now deeply ingrained in public institutions. "If we don't find intelligent ways to counter this profit extraction from public health," Paulo Picon, an academic scientist, put it to me, "we will be left with an unsurmountable indebtedness, a wound that won't heal."

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 seventy-five thousand 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.

In sum, multiple institutions and social actors dynamically meet in the Brazilian AIDS policy-space. These various institutions and actors have distinctive interests, are somewhat permeable, and mutually readjust. In practice, the AIDS policy is neither a global institution nor a novel state apparatus—it is an intermediary power formation. The policy comes into existence in the space between international agencies, global markets, and the reforming state. It is implicated in and meddles with the resources of these institutions as it struggles to intervene efficaciously. Intermediary power formations are not simply extensions of the macro or the micro; they actually exclude the immanence of both. Their operations do not follow a predetermined strategy of control and do not necessarily have normalizing effects. As is evident in the AIDS policy, their sustainability has to be constantly negotiated in the marketplace. Mobilized individuals and groups must continuously maneuver this particular therapeutic formation to gain medical visibility and have their claims to life addressed. The AIDS policy thus becomes a cofunction of governmental and market institutions, as well as individual lives.

THE WILL TO LIVE

Just as the complex Brazilian response to AIDS must be understood in the wider context of the country's democratization and the restructuring of both state and market, so, too, must it 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 states allocate public health resources differently according to the pressure of interest groups. The AIDS NGOs that were supposed to have taken over assistance "have long lost idealism and passion," as the 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."⁴

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 Torben and I returned to Caasah in December 2001, things had changed dramatically. Caasah had been relocated to a new, state-funded building. With treatment regimens available, functional 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. A nursing team now worked directly with local hospitals and admitted the patients who "fit into the institution," in the words of Celeste, still presiding over Caasah. Disturbingly, there was no systematic effort to track these patients and their treatment actively once they left.

What most interests me as an anthropologist is the process of returning to the field. Repeatedly returning, one begins to grasp what happens in the meantime—the events and practices that enable wider social and political change, as well as those that debilitate societies and individuals, dooming them to stasis and intractability. In such returns entanglements and intricacies are revealed. We witness the very temporality of politics, technol-

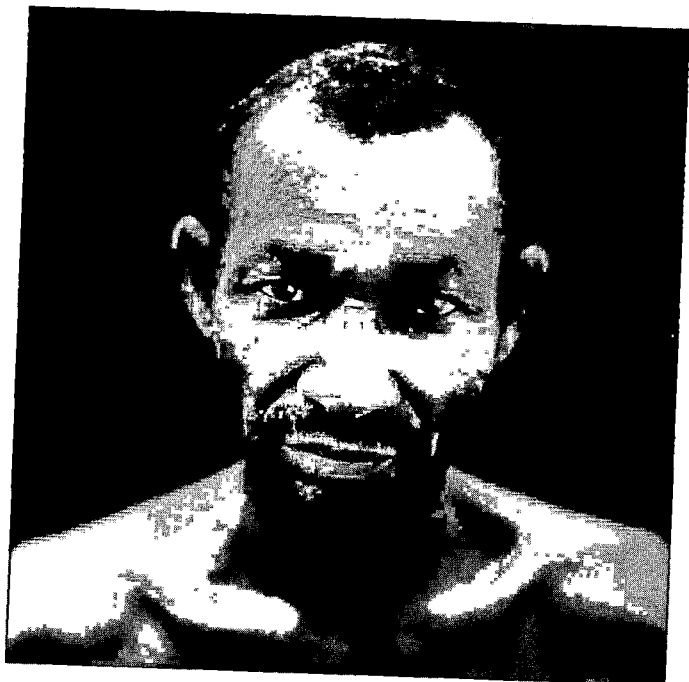
ogy, and money—how AIDS survivors move from patienthood back into personhood.

"This is a beautiful building, but that's all the state gave us," continued Celeste. Institutional maintenance was a daily struggle. "We owe more than one thousand dollars to local pharmacies. Our patients come from the hospital with their antiretroviral drugs but nothing else." The national ARV rollout was supposed to be matched by regional governments' 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.

We looked for our former collaborators and tracked down those who had left Caasah. Of the twenty-two residents we had gotten to know in 1997, ten 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 even had children. All of them had disability pensions and were entitled to a monthly food basket at Caasah. The ethnography of AIDS after the introduction of ARVs can illuminate processes of individual becoming taking place through medicines and multiple sites, relations, and intensities—fields of immanence. It is in this circuitry, as it unequally determines life chances, that AIDS survivors articulate their "plastic power" and invent a domesticity and health to live in and by (Biehl 2005a: 14).

"Today is another world," Luis Cardoso told me as he looked at the portrait Torben made of him in March 1997 (figs. 6 and 7). "One Luis has died and another has emerged. A person has to forget the past." First diagnosed with AIDS in 1993, Luis lived in Caasah from 1995 to 1999. "I have nothing to say against the antiretrovirals. 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 ARVs. I am the effect of this responsibility. 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 HIV/AIDS, and he runs prevention workshops in the interior. Even Nanci Silva, Luis's 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." As Caasah's office assistant, he earned a salary. Open about his homosexuality, he said that he was dating. Luis also proudly adopted an AIDS orphan in Caasah and was giving the boy's grandmother money to



6 Luis, 1997.



7 Luis, 2001.

take care of him. "I always believed in God, but religious talk does not help if you don't have the will to live inside you."

Luis is an amazing person, hard-working, witty, and a master of moral discourse. He speaks of a new economy of life instincts organized around AIDS therapies. And he himself is the dominant human form that emerges from this economy: "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." He has harsh words for those who throw medication away: "It's a crime."

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 *a priori* of a healthy existence, and mourning a loss, any kind of loss, was a defect to be overcome. 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* (people living on the margins of society). It was evident from his recollection that if he had not belonged to Caasah, AIDS therapies would not have had the same effectiveness for him, and that he kept harnessing strength from being the object of regular public and medical attention. His narrative of regeneration remains built on the exclusion of people like Jorge who remain invisible to the state and to medicine. Homeless AIDS patients, Luis reasons, use their social condition as an excuse to hang on to self-destructive habits: "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. Look at Rose and Evangivaldo. . . . It is your mind that makes the difference."

"Welcome to the end of the world," Rose said jokingly as we entered her brick shack, located at the bottom of a muddy hill on the outskirts of Salvador (fig. 8). "I am sold on the antiretrovirals," she told us. "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 one-year-old daughter. She had also taken in her teenage son, who had been in the custody of Caasah's

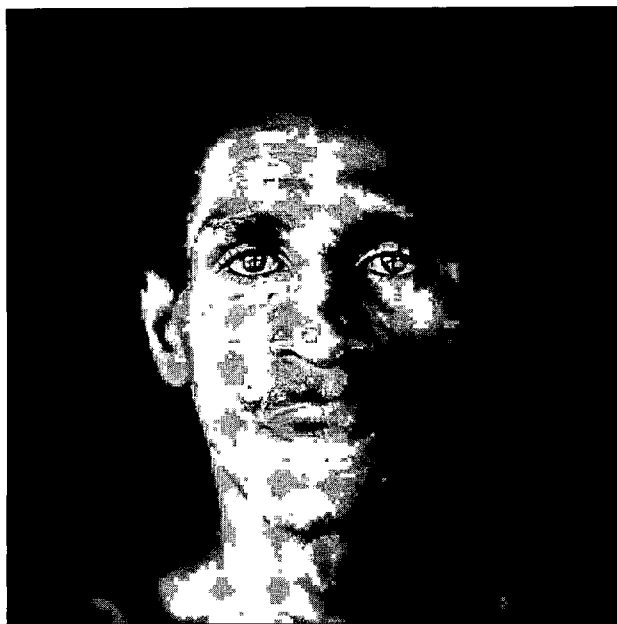


8 Rose, 2001.

chief nurse. "I am always struggling to pay the bills and raise my children, for I am mother and father."

Rose wept as she recalled the death of her partner 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 two: "She has never been ill and we hope for the best." Rose was proud to be "a good patient, but not a fanatic one. I drink a beer and have some fun on the weekends, but I know my limits, what my body can take. 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, she said, "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 guarantee-



9 Evangivaldo, 2001.

ing 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, such as renewal of disability benefits, free bus vouchers, and additional medication at local health posts. Being adopted by a doctor and becoming a model patient greatly facilitates this. This material calculus becomes all the more important as patients form new families and resume a "normal" life previously impossible for them.

Evangivaldo's face was barely recognizable, but the aesthetic side effects of antiretrovirals were the least of his concerns (fig. 9). "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 had a 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 on 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 two 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? It is because my daughter is waiting for me."

LOCAL ECONOMIES OF SALVATION

"If you look carefully, nothing has changed. Things are the same as you saw last time," a tired Celeste Gomes told me in June 2005 during my last visit. Caasah was still the only place in Salvador that provided systematic care to poor AIDS patients who have been discharged from public hospitals. "Some patients return to their families. Others go back to the streets. Disease keeps spreading, and the government pretends not to know so it doesn't have to intervene."

At the state's main AIDS unit, Nanci also said that "things here have not changed. We are 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." The unit's social worker told me that physicians triage patients. "Many doctors do not put drug addicts and the homeless on ARVs. They say that there is no guarantee that [these patients] will continue the treatment and that [the doctors] are concerned about the creation of viral resistance to medication." Against an expanding discourse of human rights and pharmaceutical possibilities, we are here confronted by the limits of the infrastructures on the ground, whereby accountability and the right to envision a new life with AIDS are (partially) realized.

Out of the initial group of twenty-two Caasah patients with whom I had worked in 1997, seven were still alive in 2005—among them, Rose, Luis, 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." Yet, as I would learn, survival

was not simply a matter discovering resources within but of inventing ways of being that enabled people to continue with their interrupted or very new lives. All of the survivors possessed a place they called home, a steady if meager income, and a social network of sorts. 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 its 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 two weeks. Davi, his adopted son, was now a healthy seven year old. "He is my passion. He makes it all worthwhile."

"What a joy you give me by coming back," beamed Evangivaldo, the kindest and most resilient man I ever met. "I can only count on the tenderness of Fatima and Juliana. 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, 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 two 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 find a job. His doctor 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 twelve pills a day, and his doctor never considered putting him on a newer medication made available by the government that required fewer pills and had fewer side effects.

Poor AIDS patients like 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, rental assistance, and specialized medical consultations, among other things. Overwhelmed with demands for help 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 patients, like thirty-year-old Sonara, manage to become "AIDS workers." She was Caasah's new poster person. A nurse introduced me to Sonara as the latter was running a candle-making workshop for a group of twelve patients: "She was a drug user, but she now takes the medication, eats well, and takes care of her daughter, who is also HIV positive." 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." There is value in conceiving the destiny of the homeless AIDS patients as self-generated, a conscious choice. The few who recover, it seems, set the limits of who is considered worthy of having a biological existence. This measure informs intersubjectivity and makes triage commonsense.

To have someone to live for and to be desired by seemed to be a constant thread in accounts of the AIDS survivors with whom I worked. All of them had engineered tiny islands of hospitality in which they can inhabit life. Yet they also acted coldly toward fellow patients. 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. The previous day over the phone she had asked me to do this for her. I told Luis and others at Caasah, but my request met a series of obstacles: "The basket isn't ready"; "There's no one here to sign it out"; "I don't have time"; "We have to go."

Rose was doing great, as were her children. As for the food basket she was, of course, disappointed: "But that's life. Onward." She had garnered the support of NGOs and opened up a little business she called *Rose Tem de Tudo* ("Rose Has It All") and had also devised a fundraising campaign to improve her housing. Rose was also proud of having been able to enroll her son in the project Adolescent Citizen, which Dona Conceição was now

running with World Bank funds. Later that week, I met with Dona Conceição, who regretted that Caasah remained the only institution addressing AIDS on 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."

CONCLUSION: LIFE TECHNOLOGIES AND HOPE

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 interactions between state and regional actors and nongovernmental and grassroots organizations underlying various communal and individual modes of life that have emerged around ARVs in one of the country's most vulnerable urban populations. In highlighting the successes, failures, and complexities of the Brazilian response to AIDS, I have revealed significant 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.

Yes, 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, burdened by labels such as *drug addict*, *prostitute*, *beggar*, and *thief*—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 social and economic rights for the poorest remain largely unavailable.

Drugs are ancillary to the full treatment of disease. Healing, after all, is a multifaceted process, and large-scale treatment programs tend to miss the interpersonal networks that link patients, drugs, families, and health professionals, which are especially important in resource-poor settings where infrastructure is often not improving.

This elision of the local from planning frameworks leaves unaddressed the clinical continuity necessary for successful AIDS treatment. The responsibility for damaging side effects should not be left to the patients themselves but should be guarded against by more and not less preventive policy making. Likewise at issue is a reconsideration of the systemic relation of pharmaceutical research, commerce, and public health care. We should search for a more sustainable solution to the obstacles posed by patentability and pharmaceutical business control over medical science and health care on the ground. Part of the solution may lie in comprehensive knowledge and technology sharing among southern countries—a paradigm that would allow poorer countries to develop effective health technology assessment programs, pool their manufacturing know-how, and unite in negotiating fair prices. Moreover, high-technology interventions must be reconciled with systems that foster the equitable inclusion of populations into preventive as well as basic and sustained care initiatives.

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 have plunged into new environments. By all standards, they have exceeded their destinies. Now receiving treatment, Rose, Luis, Evangivaldo, and many others refuse the condition of leftovers; they humanize technology and remake themselves in familiar terms. 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. Theirs is the force of immanence—call it a language of hope.

NOTES

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- 1 Caasah is an acronym for 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.
- 2 See the press release by IMS Health (March 21, 2006): "IMS Health Reports Global Pharmaceutical Market Grew 7 Percent in 2005, to \$602 Billion," <http://www.imshealth.com/> (downloaded on February 10, 2010).
- 3 The work of Paul Farmer and Partners in Health provides an opposing community-based model for AIDS treatment (Walton et al. 2004). "Improving clinical services can improve the quality of prevention efforts, boost staff morale, and reduce AIDS-related stigma," writes Farmer (2002b). 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 impact their families and mitigating the decay of clinical infrastructure.
- 4 The anthropologist Marc Abélès (2006) has been studying the dual displacement in governmentality and resistance that accompanies the work of NGOs as "life and survival" are put "at the heart of political action." He argues that "a sense of powerlessness has become the backdrop for political action. It is as though the citizen's capacity for initiative were going through a more or less explicit reassertion of this admission of powerlessness, tied to the awareness of a radical reappraisal of our terms of belonging. The other side of this position is a projection towards a vaguer collective interest relating more to survival (*survivance*) than to the art of harmonious living together (*convivance*)" (493-94).