Introduction

A New World of Health

The Right to a Nonprojected Future

In his book *A Bias for Hope*, economist Albert O. Hirschman (1971) challenges social scientists to move beyond categorical prejudgments, beyond the sole search for general laws and orderly sequences of what is required for wider social and political transformation. Having in mind the Latin American countries in which he worked (including Brazil), Hirschman challenges us, instead, to engage the *unexpected*.

The study of how beliefs, attitudes, and values are refashioned and molded by "more or less accidentally undertaken practices," Hirschman argues, "widens the limits of what is or is perceived to be possible, be it at the cost of lowering our ability, real or imaginary, to discern the probable" (p. 28). At stake is helping "to defend the right to a nonprojected future as one of the truly inalienable rights of every person and nation; and to set the stage for conceptions of change to which the inventiveness of history and a 'passion for the possible' are admitted as vital actors" (p. 37).

This book addresses the crucial question of what happens when such luminous prospects of social science are politically and technologically operationalized. Brazil has, against all odds, invented a public way of treating AIDS. In 1996, it became the first developing country to adopt an official policy that universalized access to antiretroviral drugs (ARVs), about five years before global policy discussions moved from a framework that focused solely on prevention to one that incorporated universal treatment. Some 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 in the developing world. This lifesaving policy came into existence through an unexpected alliance of activists, government reformers, development agencies and the pharmaceutical industry. *Will to Live* moves between a social analysis of the institutional practices shaping the Brazilian response to AIDS and the stories and lives of people affected by it.

HIV/AIDS is the first major epidemic of present-day globalization. Of more than 40 million people estimated to be HIV-infected worldwide, 95 percent 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. 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 lived in Brazil (UNAIDS 2004). 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 (UNAIDS 2006). Brazil, with less than 3 percent of the world's HIV/AIDS cases, still accounted for nearly 15 percent of people on ARVs.

Throughout this book, I examine the value systems and the political and economic factors underlying the Brazilian AIDS policy, and identify the novel power arrangements (both national and global) that are crystallized in the policy, in its articulation and implementation. As I probe the policy's social and medical reach, particularly in impoverished urban settings where AIDS is spreading most rapidly, I also inquire into the micro-politics and desires that invest ARVs, making survival possible.[1] I draw from research I carried out over the past ten years among people working in state, corporate, scientific, and nongovernmental institutions, and also from fieldwork among marginalized AIDS patients and grassroots care services.

To understand the radically different world of AIDS post-treatment access I had to move in time and space, back and forth between a difficult analysis of how the afflicted understand themselves—born of careful ethnographic work and long-term conversations I was privileged to have—and a more experience-distant investigation into how therapeutics mix with activism and political economy: locally, nationally, and globally.[2] Fieldwork allows us to see these various actors and forces at work, reminding us that there is no short cut to understanding the multiplicities of reality and the practical articulations through which technologically extended life happens. Ethnography remains, in my view, a vital social scientific antidote to what Hirschman identifies as "compulsive and mindless theorizing." As he writes, "Quick theoretical fix has taken its place in our culture alongside the quick technical fix" (1970, p. 329).

Although much of my research stands within the traditional boundaries of ethnography (charting the lives of individuals and institutions over time through open-ended interviews and participant observation), I also make use of alternative forms of evidence—some of them quantitative—developed in collaboration with researchers and practitioners from other disciplines, including epidemiology. Yet during my fieldwork, I often found myself returning from what I "[saw] and heard with bloodshot eyes and pierced eardrums."[3] Where words and numbers fell short, I teamed up with photographer Torben Eskerod; his photographs, interspersed throughout these pages, highlight the plight and singularity of the abandoned AIDS patients with whom I worked.

Examining this constellation of evidence from an anthropological perspective sheds light on how scientific and technological developments, medicine, and political-economic institutions do their work over time and across cultures. Biotechnological innovations engender unlikely coalitions that both expose the inadequacies of reigning public health paradigms and act to reform, if to a limited extent, global values and mechanisms (of drug pricing and types and scope of philanthropic and humanitarian interventions, for example). Mediated by an activist state, these therapeutic coalitions also expose national contradictions and bring about novel institutions, modes of life, and inequalities. Brazil's response to AIDS thus provides a unique opportunity both to apprehend shifting public-private involvements in a neoliberal landscape and to assess their immediate and long-term effects.

Some of the questions that guided my ethnographic and social epidemiological 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 the state of human rights, politics, and equity on the ground and globally? Which forms of health are sufficient to liberate life, wherever it is confined?

Universal Access to Lifesaving Therapies

Brazil is the epicenter of the HIV/AIDS epidemic in South America and accounts for 57 percent of all AIDS cases in Latin America and the Caribbean.[4] AIDS was first reported in Brazil 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. At the end of 2001, an estimated 610,000 individuals were living with HIV/AIDS (an adult prevalence of 0.7 percent).

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. In 1998, 18 percent of sex workers tested in São Paulo were HIV-positive, and in certain areas of the country, intravenous drug users contribute to almost 50 percent of all AIDS cases. Since 1998, the death rate from AIDS has steadily declined, an achievement attributed to the country's AIDS policy (Okie 2006; Dourado et al. 2006).

In the Brazilian AIDS world, the vital actors with a passion for the possible were not just professional politicians. 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. 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.

Social mobilization forced the government to democratize its operations further. AIDS activists and progressive health professionals migrated into state institutions and actively 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 they received from intellectual property rights laws and the World Trade Organization (WTO) had artificially put these therapies out of reach of the global poor. After framing the demand for free and universal 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 drugs and promoting the production of generics in both public- and private-sector laboratories. 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.

The result—a policy of biotechnology for the people—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 subsequently fallen by 70 percent (MS 2002). Known for its stark socioeconomic inequalities and its perpetual failure to develop to its full potential, Brazil has faced down AIDS, at last becoming "the country of the future" that idealist Stefan Zweig (1941) imagined in the 1940s.

The Brazilian treatment rollout has become an inspiration for international activism and a challenge for the governments of other poor countries devastated by the AIDS pandemic.[5] This policy challenges the perception that treating AIDS in resource-poor settings is economically unfeasible, and it calls our attention to the ways in which biotechnology can be integrated into public policy even in the absence of an optimal health infrastructure.[6] It likewise opens up the political and moral debate over delivering life-extending drugs to countries where patients are poor and institutions have limited capacity, as well as the debate over the immediate and long-term medical implications of doing so.[7]

By 2000, the Brazilian national AIDS program had been named by UNAIDS as the best in the developing world, and in 2003 it received the $1 million Gates Award for Global Health. Brazil is now sharing its know-how in a range of ways. It has taken on a leadership role at 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.

We are still far from achieving international justice in the realm of AIDS, but the Brazilian response has at least helped to expose the failures of reigning paradigms that promote public-private partnerships for the resolution of social problems. Brazil's national response has also shown the limits of international development agencies when confronted with the need to act directly on behalf of the poorest. Practically speaking, Brazil opened channels for horizontal south-south collaborations 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 destine their populations to disease and ill health.

A Political Economy of Pharmaceuticals

Although a compacted and all-encompassing sovereignty is hard to locate in today's geopolitical order, states do not necessarily weaken amid economic globalization.[8] But they do reform and reconfigure themselves, developing new strengths and novel articulations with populations. 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."

Cardoso 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. "Government and social movement practically fused. Brazilian society now organizes itself and acts on its own behalf." From this perspective, the state appears through its model policies.

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 this book's central arguments is that on the other side of the signifier *model policy* stands a new political economy of pharmaceuticals, with international and national particularities. As NGO activism converged with state policy making, and as the public health paradigm shifted from prevention to treatment access, political rights have moved toward biologically based rights.

Neoliberal governmentality has taken a new shape. Rather than actively seeking areas of need to address, the new market-oriented state selectively recognizes the claims of organized interest groups that "represent" civil society, leaving out broader public needs for life-sustaining assistance—in the domains of housing, economic security, and so forth. To be "seen" by the state, people have to join these groups and engage in lobbying and lawmaking.

Ethnography helps to uncover the circumstances and contradictions that are inherent to this novel form of therapeutic mobilization, already abstracted in Cardoso's articulation of a "mobilized Brazilian society" and a "porous and activist state." Ethnography complicates. It is a way of grounding and dissecting such abstractions, illuminating the contingency, multiple interests, and unevenness of the political game that is under way.

Given the increasingly global frames of disease control, the way a state deals with AIDS reveals its statecraft: in the Brazilian case, engagement with—and submission to—the forces of globalization. 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 the developing countries that supported the creation of the WTO, and it had signed the Trade-Related Aspects of Intellectual Property Rights treaty (TRIPS). Parallel to the new patent legislation, pharmaceutical imports to Brazil have increased substantially. Currently, Brazil is the eleventh largest pharmaceutical market in the world.

As the AIDS policy unfolded, Brazil attracted new investments, leading to novel public-private cooperation over access to medical technologies. While Brazil experimented with new modes of regulating markets for lifesaving treatments, pharmaceutical companies took the conflicts over drug pricing and the relaxation of patent laws at the WTO as opportunities both to negotiate broader market access in Brazil and to open up unforeseen AIDS markets in other countries. The industry has also been able to expand clinical research in Brazil, now run in partnership with public health institutions. American pharmaceutical companies have at the same time successfully downplayed the WTO as they lobbied for strict bilateral and regional trade agreements that made local production of generic drugs unviable.

Global markets are incorporated via medical commodities. This process is mediated by development organizations and has crucial implications 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. The Brazilian AIDS policy was aligned with a pharmaceutically focused form of health delivery that was being put into practice as part of the government's vision of cost-effective social actions (involving the decentralization and rationalization of assistance amid the dismantling of public health institutions). In recent years, Brazil has seen an incremental change in the concept of public health, now understood less as prevention and clinical care and more as access to medicines—what I call the *pharmaceuticalization of public health*.

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. Despite the allegedly universal reach of the AIDS policy, poor AIDS patients have not been explicitly targeted for specific governmental policies related to housing, employment, or economic security. The urban poor 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.

Medicines, as I argue throughout this book, have become key elements in the state's arsenal of action. As AIDS activism migrated into state institutions, and as the state played an increasingly activist role in the international politics of drug pricing, AIDS became, in many ways, the "country's disease." In May 2007, for example, Brazil broke the patent of an AIDS drug (Efavirenz, produced by Merck) for the first time—a step recently taken by Thailand—and authorized the import of a generic version from India. Activists worldwide hailed this sovereign decision as a landmark in struggles over the sustainability of countrywide treatment rollouts. Yet, while new pharmaceutical markets have opened, and ARVs have been made universally available (the state is *actually* present through the dispensation of medicines), 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.[9] My ethnography illuminates how 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 those in the marginalized underclass by the wayside. These individuals cope by using survival strategies that require extraordinary effort and self-transformation.

Persistent Inequalities

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 must it be seen in light of its interaction with local worlds and the subsequent refiguring of personal lives and values.[10]

I was in the coastal city of Salvador (the capital of the northeastern state of Bahia) conducting fieldwork when ARVs began to be widely available in early 1997. For the previous two years I had been charting the local politics of AIDS and documenting life with AIDS among the homeless and the residents of Caasah, a grassroots health service.

Considered by many the "African heart of Brazil," Salvador has an estimated population of 2.5 million and is a center of international tourism. The capital of the country until 1763, it was the entry point for millions of slaves brought from West Africa. Bahia, the largest state in the northeast region of Brazil, has a population of some 12.5 million.[11] Forty-one percent of Bahia's families live below the country's poverty line, and the top income quintile holds 69.5 percent of the wealth in the state. With about 70 percent of the total AIDS cases of the state, Salvador lies at the center of Bahia's AIDS epidemic.

Local epidemiologists and public health officers in the late 1990s had 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 I saw in the streets of downtown Salvador contradicted this profile. A large number of AIDS sufferers remained epidemiologically and medically unaccounted for, thereafter dying in abandonment. Meanwhile, community-run initiatives triaged care for some of the poorest and sickest.

A central concern of my ethnography has been to produce alternative epidemiological evidence and to generate some form of visibility and accountability for the abandoned subjects with AIDS.[12] As anthropologist-physician Paul Farmer has shown in the context of AIDS in Haiti and the United States, inequalities of power, ranging from poverty to racial and gender discrimination, determine who is at risk for HIV infection and who has access to what services (1992, 1999, 2003). By working closely with those who deliver care to the neediest and by attending to and documenting these patients' voices and experiences, one can identify and weigh the social factors promoting HIV transmission. One can also illuminate variations in the course of disease and in the value systems that lie within medical infrastructures. How, I wondered, would the ARV rollout fare in that context of multiple scarcities and ineffective regional politics? How would the most vulnerable transform a death sentence into a chronic disease? Which social experimentation could make such medical transformation possible?

Here, Hirschman's "right to a nonprojected future" begs for enactment and institutionalization. Caasah, a focal point of my research, was founded in 1992, when a group of homeless AIDS patients, former prostitutes, transvestites, and drug users squatted in an abandoned maternity ward in the outskirts of Salvador. "Caasah had no government," recalled Celeste Gomes, Caasah's director. "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, perhaps surprisingly, 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 resources for basic maintenance. Caasah had formalized partnerships with municipal and provincial Health Divisions, buttressed by strategic exchanges with hospitals and AIDS NGOs.

Throughout the country, other "houses of support" (*casas de apoio*) like Caasah mediate the relationship between AIDS patients and the haphazard, limited public health care infrastructure. They address the paradox that medication is available, but public institutions are barely functioning. By 2000, at least one hundred of the country's five hundred registered AIDS NGOs were houses of support. However, in order to belong to these makeshift institutions of care, people must break with their old habits, communities, and routines as they forge new biographies.

By the mid-1990s, the unruly patients in Caasah had been evicted, and a smaller version of the group began to undergo an intense process of resocialization mediated by psychologists and nurses. Eighty "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 post, 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 Celeste put it, "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."

Caasah's residents and administrators constituted a viable public that effectively sustained itself in novel interactions with governmental institutions and local AIDS services. In this "AIDS-friendly environment," people did not have to worry about the stigma that came with having AIDS "on the outside," and there was scheduled routine and an infrastructure that made it easier to integrate drug regimens into the everyday. At least for some, this unvarnished public—as desperate as it was creative—came to shape not only adherence to the ARVs but another chance at life.

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To document this particular public, to do justice to the singularity of its many lives, photographer Torben Eskerod joined me in the field in March 1997. With a simple chair and a black cloth against a wall, we improvised a photography studio outside Caasah's main building. Torben photographed each person as he or she wished to be portrayed, and I recorded their stories, past and present.

When we returned in December 2001, things had changed dramatically. Caasah had been relocated to a new state-funded building (though it remained an NGO). With treatment regimens available, functional residents had been asked to move out, and Caasah had been redesigned as a short-term care facility for ill patients (a "house of passage," *casa de passagem*) and a shelter for HIV-positive orphans. The hospice now had a team that worked directly with local hospitals and admitted the patients that “fit into the institution and its norms,” in the words of Celeste. Disturbingly, there was no systematic effort to track these patients and their treatment actively once they left.

At the state hospital I learned of a triage system for AIDS patients, of which Caasah is part. “Homeless AIDS patients remain outside the system,” one of the hospital’s social workers 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 development of viral resistance to medication.” The hospital’s leading infectious disease specialist confirmed that “in theory, obviously, the doctor cannot withhold ARVs from drug users and homeless patients . . . but the fact is that the homeless patient does not return for routine ambulatory checkups. So what I do is tell the patient that he has to come back. If he returns and demonstrates a strong will, we begin treatment. . . . But they never, or rarely, come back.”

We looked for our former collaborators and tracked down those who had left Caasah. Some had died; others had survived, married, and had children. As Torben took their portraits once again, they told us about all sorts of financial pressures, battles over discrimination, and the difficulty of obtaining access to quality health care. They told us about their *will to live*.

The patients photographed by Torben intimately engage us, their faces and words relating personal travails and the larger issues surrounding AIDS treatment and social inequality. Their very presence, brought so close to us through Torben’s lens, establishes an alternative register of engagement and meaning that animates this book: How do these subjects both reflect one another and differ among themselves? What makes them visible or invisible in their neighborhoods? What is their place in a nation’s order and in new medical regimes? How do we relate large-scale institutions and forces to local politics and personal trajectories? What is the staying power of these subjects’ interior force of life? What might their stories, standing alone and taken collectively, suggest through their concatenation? Each dimension merits a closer look.

In this ethnographic work, double takes were both literal and figurative. Our 1997 work redoubled when we returned to Caasah four-and-a-half years later, providing us with a distinctive longitudinal perspective. And comparing these different moments in time—then and now—in turn opened a critical space for examining *what happens in the meantime*. Our methodology thus operated in dialogic, open-ended, and reflexive fashion: moving back and forth, across time and space, to offer a distinctive understanding of private and public becoming in the face of death and AIDS therapies.

Lives

“Take me to my father’s house”

Edileusa came out of the building and into the backyard, where Torben and I had arranged the outdoor studio. She confronted us with a request: “I want to leave. I was waiting for you to come and take me away. God sent you.”

Abruptly, she sat in the chair in front of the camera. “You can see how I look into it.”

Edileusa had been in Caasah’s triage room for the past twelve days, and this was her first day out. She had worked as a prostitute from an early age. The administrators and nurses knew very little else about her past or about the progression of her disease.

Edileusa continued: “But now I am cured. I am God’s daughter. I had an ulcer. It is healed. Virgin Mary, it is so good to be free, a free person.”

She remembered being expelled from home. “They were ashamed of me. They said that I had stained their lives.” But now “my blood is clean. I took all exams; their results are in the infirmary. . . . See, I don’t have marks on my body.”

Edileusa kept staring straight into the camera. “Nobody likes me here. My things are ready. Put me in your car, and I will tell you where to leave me.”

Where to leave you?

“Take me to my father’s house.”

She looked down. I tried to explain to her that we could not take her away, that she was recovering, that we were doing a work of . . .

“Then it is already done,” she declared, and she left.

The next day, I looked for Edileusa in her room, but she was not there; she was back in the triage room. Two weeks later, she died.

Edileusa, 1997

“Today is another world”

“My name is Luis Cardoso dos Santos. I am thirty-six years old. Do you want me to close my eyes? You know, even when I am asleep, I sense when someone is coming into the room. My unconscious is very special. It makes me foresee things.”

Luis was brought up by his mother, a *mãe de santo* (a priestess in Candomblé, a traditional Afro-Brazilian religion): “At the age of nine my head was shaved, and I was also initiated as a child-saint.” Luis did not finish elementary school: “I had to work. I sewed clothing and later, I will not deny it, I smuggled goods from Paraguay.”

Luis had lived in Caasah since 1995. “As you might have noticed, *I was* a homosexual—not a crazy one, though. Today *I am* a patient. I work for Caasah.” The administration hired Luis as an office assistant, and he also helped to take care of Tiquinho, a fifteen-year-old hemophiliac boy who had grown up in Caasah.

“For two years, I had been weak, going to the ambulatory services, but the doctors never found out what I had. Finally, they drew my blood for an AIDS test. With the test result, the world closed for me. My family and friends discriminated against me. For them, AIDS was a crime. A doctor sent me here,” remembered Luis. Caasah’s nursing team helped Luis “to disembark from that death trip.”

Luis loved to spread the word about his revival: “Soon I saw that one Luis had died and that another had emerged. Day after day, I feel better. I always try to bring the other patients a friendly word; we all need a friendly word. I will not give death any chance to come near me anymore. If death wants me, it must search for me.”

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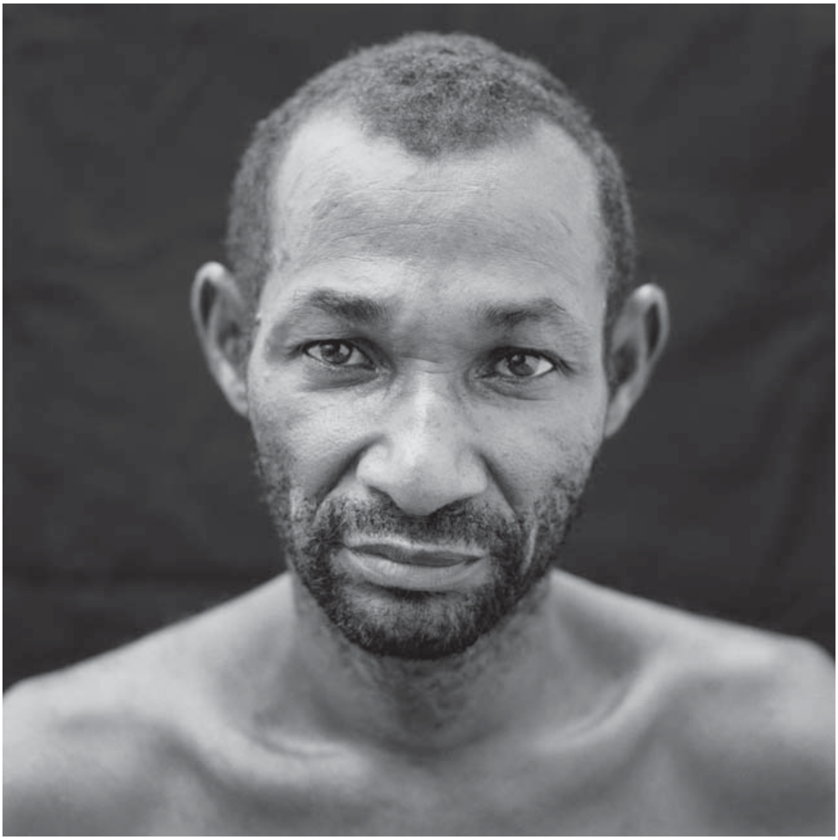
“Today is another world,” Luis told us, as he looked at the portrait that Torben had made of him in 1997. “I have nothing to say against the antiretrovirals. I am under Dr. Nanci's care, a very well-known and respected doctor. Celeste and the psychologists motivated me a lot. But I don't live here anymore, and I must take care of myself. I got used to the medication. Medication is me now."

A disability pension and the salary he was earning as Caasah's office assistant allowed Luis 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."

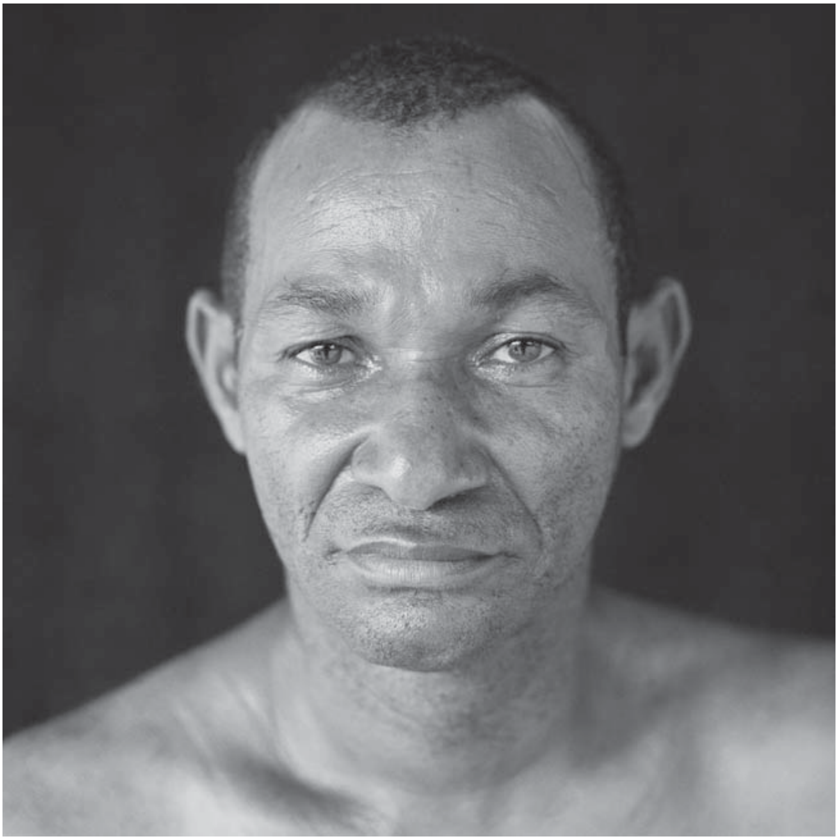
"I don't stop to analyze. What is past does not interest me. I came to face AIDS as a routine, like jumping from bed, brushing my teeth. Medication is a breakfast, and, as a breadwinner, I must go to work. . . . I can be well and then all of a sudden one day fall ill. I must adapt to this movement and face every specific problem. Today AIDS is both struggle and hope."

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.

"I go step by step, pushing life forward with my will."



Luis, 1997



Luis, 2001

“If I only had thought then the way I think now”

Rose’s left hand was atrophied, and she limped. “It is all from drug use. See my hands? I hit the nerves, and they had to cut two fingers.” She did anything to get drugs: “I robbed and prostituted myself. 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 thirteen, after she became pregnant. She moved into Pelourinho’s red-light district (in Salvador’s colonial compound). By the early 1990s, as she saw her friends dying, she realized that “the party was over.” 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. The father of one of Rose’s babies was a founding member of Caasah.

One by one, Rose gave up her four children for adoption (the youngest was adopted by Naiara, Caasah’s vice president). “What else could I have done? I couldn’t give them a house. I would like my children to know that they were not raised by others because of abandonment, but because of my lack of experience—and also because I thought that I would not live much longer.”

Rose has lived longer than she expected. For four years, she has officially been off illegal substances. She has remained asymptomatic, has become literate, and has learned to make handicrafts. At the time of the photograph, she was involved with Jorge Ramos, another resident, and

Rose, 1997

was beginning to take ARVs. “I take life in here as if it were a family, the family I did not have,” she stated.

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“Welcome to the end of the world,” Rose said jokingly, as we entered her brick shack, located at the lower end of a muddy hill in the outskirts of Salvador. “I am a new creature, you can write my story.” She told us, “I am sold on the antiretrovirals. I am part of this multitude that will do whatever is necessary to guarantee our right to these therapies. 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 under the custody of Professor Carlos, Caasah’s nurse. “I am always struggling to pay the bills and raise my children, for I am mother and father.”

Rose wept as she recalled how Jorge had died 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, “and I pray every day for this to happen.”

That same week we met with Rose’s doctor. She expressed great respect for the way Rose takes care of herself and navigates the meager and largely unequal networks of care.

“I love Dr. Nanci,” Rose told us. “She is a blessing to me and my family. She supports those who want to live. I never had another doctor, and I never had this problem of having to change treatment.”

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.”

Yes, “people are still dying with AIDS in the streets,” she stated, “but I am no longer there.”

Rose, 2001

“Why will I think about the future?”

Nerivaldo stumbled over the chair in front of the camera. Scars from drug injections marked his arms, neck, and forehead. “If all was so simple,” he murmured, as he took off his shirt for the portrait. His hormone-induced breasts had almost disappeared. Nerivaldo had begun injecting drugs at a very young age, and he turned tricks as a transvestite until he suffered a stroke three years ago. “First it was the foot; it got a little diseased. Then it was the hand, and I was paralyzed. I recall the doctor saying, ‘It is all over.’”

Nerivaldo’s face shifted, and his eyes opened and closed erratically, making it impossible to get a clear, still shot. “I have a cataract. It is very difficult to see.” Torben then moved the camera closer, as Nerivaldo fought his blindness.

Now in his late twenties, Nerivaldo grew up in the streets. His mother died when he was eight years old. “I have a father, but I do not know where he is.” Nerivaldo had lived in Caasah for a few months in 1995, but he did not comply with its strict discipline and medical routine, so he left. He wanted to live his life on his own, familiar terms: “I wanted to enjoy myself as much as I could, to play with my friends out there.”

Sometime later, one of Caasah’s leaders found him begging in a church, suffering from wounds infected with maggots. Nerivaldo was offered a last chance. He praises the regular care he gets now: “They bandage me up, give me medicine. No one has ever done that for me.”

But how is it to live in Caasah?

“It is a depression.” Depression springs from the experience of Caasah, an experience in which people are simultaneously well and sick: “We see some dying and others recovering. It’s all there is.” A resigned understanding of his place in history binds Nerivaldo to this reality. “I am already an *aidético* [a person with AIDS]. Why will I think about the future?”

Nerivaldo, 1997

Nerivaldo related a dream from the night before. “I was first talking alone, to myself. But then I was talking to myself with another person.” When asked if he remembers a face, he answers, “My mother. My mother is dead. She died giving birth to my sister. So there is no way I can see my mother. I said, ‘Mother, mother.’ She responded, ‘My son, my son.’ Only this. That’s how I speak in the dream. I see nothing.”

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We were told that Nerivaldo had left Caasah again only a few months after the 1997 photograph was taken. He lived with his lover in an abandoned building in downtown Salvador. He fell ill again and found refuge in a makeshift asylum, Casa de Mãe Preta, where he died in 1998.

“A child is what I wanted most in life”

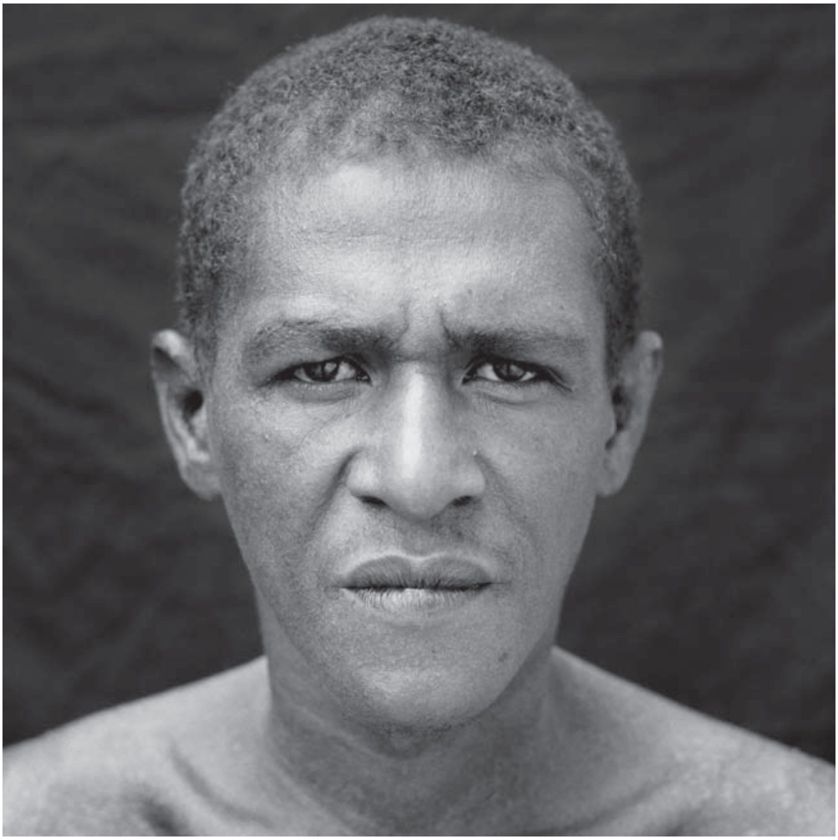
“I have the need to talk, to speak all truths,” Evangivaldo proclaimed. “I have this sad psychosis in my head, but nobody comes in here.” He spoke to us through a door from his quarantined room.

A former street inhabitant, Evangivaldo was being treated at the AIDS unit of the state hospital. Despite his extremely contagious, crusted Norwegian scabies, a social worker had sent him to Caasah with a “satisfactory discharge.” Itches and scabies soon spread throughout Caasah. Healthier residents had developed a strong contempt for anyone who posed a danger to their immune systems, and they urged the administration to send Evangivaldo back to the streets.

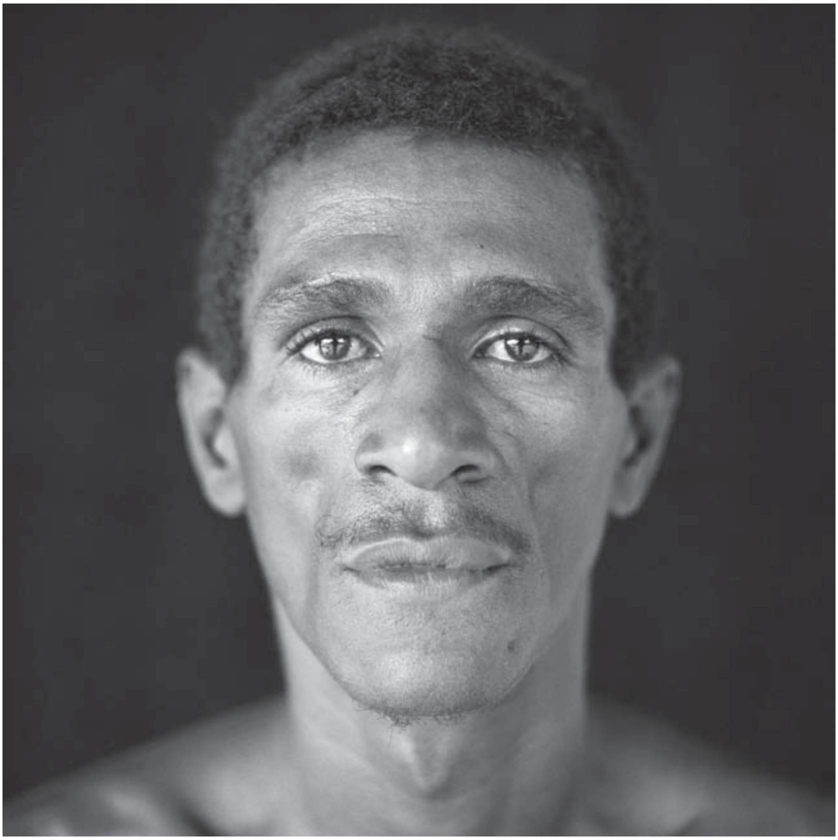
Evangivaldo asserted that his greatest fear was not AIDS, but rather what he termed “AIDS citizens”: “There are people in here who think that they are superior because of the color of their skin, or because they have a doctor who likes them, or because they have a better health condition. The other day, a guy hit me on the back. But I am not someone who creates confusion. Who knows, the guy could even do something bad to me; he could kill me. They do not do medical autopsies here.”

As we were ending this photographic work, Evangivaldo asked to be photographed. He sat in the chair. “I feel a bit different now that I have someone to talk to. As if I were sleeping . . . I dream with birds, trees, and myself at the river shore. The time I lived in the interior, cleared the land, planted manioc, made it into flour, and cut wood. I was left alone, the only child, and came to Salvador in 1980. I carried tons of flour on my back to buy a pair of sandals.

“Later, my work was to take prostitutes to the ships that docked here. Greeks, Filipinos, Koreans, Africans, Chileans, Europeans, I saw all those orgies. . . . An Italian man once gave me gifts. Women were never so tender to me. I am sure he did not infect me. I felt this desire—how can I say it?—it was love. He told me of those landscapes he had seen. He never



Evangivaldo, 1997



Evangivaldo, 2001

returned. Now I think that had I traveled away, none of this would have happened; rather, other novelties."

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"What a joy you give me by coming back," beamed Evangivaldo. His face was barely recognizable. But the aesthetic side effects of ARVs were the least of his concerns. "Today I woke up anguished. We had no gas to cook. I hope you can help me."

For the past three days we had tried in vain to reach him. We had a wrong address and no telephone. "I already had to move four times, because people discovered that Fátima and I have AIDS." The couple had met at Caasah and now had a two-year-old daughter. Juliana was born HIV-positive, but after eighteen months her HIV status changed. "She is healthy now. . . . 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, but now I have a fruit of the earth."

Still on antipsychotic medication and fighting stigma, Evangivaldo explained that although he and Fátima took ARVs, the couple had no way to pay for medication to treat opportunistic diseases, and they were now badly in debt at the local drugstore—a common story, according to Caasah's director.

"It is the financial part of life that tortures me," Evangivaldo said. "When I see them with no food, it makes me ill. But when I find a job and there is nothing lacking at home, then for me it is another life and it is all good."

We sat under a tree in Caasah's backyard, and Evangivaldo looked at his 1997 photograph: "This work was important to me, it marked my history. Then I thought that I would not live. So many of those who thought they were the big guys of Caasah are already dead. My politics is to see things humanly. The one who is strong now must help the weaker."

“To have HIV . . . is like not having money”

When I first saw Valquirene in October 1996, she walked around the compound with a cloth over her head, and whenever she was in her room she threatened to throw herself out the window. Her family had left her in a psychiatric institution, where she had been given antipsychotic medication, and finally she had been dropped off, “like a carcass,” at Caasah. “The doctors and my mother made me crazy,” she told me.

Caasah’s nurses eased her away from her chemical dependence. In early 1997, she became the first patient at Caasah to be treated with the ARVs recently made available by the government. Three months later, she had acquired, in her own words, “twenty-two pounds and a new body,” and was ready to move out of Caasah.

Valquirene, wearing a black cap, approached us with some hesitation. She said that she had lived through so much that she too wanted a portrait made. As she sat, I told her that she could put her head down or show only her back, if she preferred. Instead, she took off her cap and used it as a mask. Her eyes were strikingly blue. She later told us, “I look like my maternal grandfather. He was German and married a black woman. My father’s parents were Portuguese and Indian.”

With the new therapies, she says, “I have no fear of living. I am only afraid of dying because of my son. I want him to study, to be a great man—then I can die.” Valquirene was learning to do handicrafts to maintain herself and planned to study computing. “These days, you need the English language.” She had also sought the advice of an activist lawyer, who was helping her to regain custody of her two-and-a-half-year-old son.

“I think that I am a different person now and that it is not such a bad thing to have HIV. It’s like not having money. And, in Brazil, everybody experiences that.”

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Valquirene regained her health and the custody of her child. She never returned to Caasah for further assistance. Former residents at Caasah reported that she had found a boyfriend, also HIV-positive, and moved with him to the interior, where she ran a food stand. Some said that Valquirene had taken the child with her, while others said that she had left the child under the care of her mother.

Valquirene, 1997

“Too much medication”

“My image will burn the negative. I am too ugly. . . . What are you doing?”

“Measuring the light,” Torben answered.

“Sometimes the eyes say something and the face says something else.”

Soraia closed her eyes.

“My head is airy now, too much medication. I forget the room I am in. Sometimes I put something in one place, but then it is not there; I put it somewhere else.”

It was Soraia’s second day out of the triage room. Twenty-two years old, she had migrated from a rural area in the south five years earlier. Before going to the hospital and then to Caasah, Soraia worked the streets of upper-class Pituba Beach as a prostitute. Because of her white skin, she was a prized commodity.

Soraia believes that she was contaminated with HIV by madmen. “They took me by force, held me down, and I could not react.” Later, she mentioned having to leave her home in the south because “my brothers beat me up. . . . My parents are both dead.”

Only in the hospital did she find out that she had AIDS. “I thought my life was over. I took a piece of glass and began cutting my wrist, but the nurse found me. I did not sleep, I did not eat; I only wept in the hospital.”

Soraia was renting a house with two other prostitutes and their four children. But when she left the hospital, her housemates kicked her out, saying that she would contaminate their children. “I had many things. I had a refrigerator. They took everything, even my clothes.

“It is not good to be imprisoned, but I must get used to being in Caasah. You know, all these pills are in fact a kind of drug. Sometimes I feel doped, I get crazy, but then it passes. It is good to take them, right? To cure, to be well.

Soraia, 1997

“Last night, I dreamed about my family. I came home at night and wanted to sleep. My sister told me that I should not go to bed, that I was no longer allowed to live there. Then I went to the street, and all of a sudden I was ambushed. A nurse then woke me up to take medication. . . . I don’t know anything else. I lost the sense of the future. Now I have nothing to lose.”

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Former residents told us that Soraia had left Caasah in 1997 and that she had resumed prostitution for a while. But for several years thereafter, she had not been seen.

“A beautiful place”

Tiquinho, a child with hemophilia, grew up in Caasah. A transfusion of HIV-tainted blood infected him at a young age, and the mayor of his tiny town, Rio Leal, forced him to leave. Now fifteen years old, he goes back to the interior once a year, during Christmas, to visit his mother and eight siblings.

Tiquinho was mostly silent in our meetings. Now and then, he whispered a few comments: “When they told me I had AIDS, it made me nervous. But I began to understand that what I have is not the end of the world. I am not a person who demands things. Sometimes when I am in pain, it takes a long time for people to know what I am feeling.”

One day, he drew a house with a Brazilian flag on it: green for forests, blue for the sky, yellow for gold, white for peace, full of stars, and without the slogan “order and progress.” Tiquinho is illiterate. On another piece of paper, he drew a smiling babylike creature, big and in diapers, with a woman coming out of the head, her mouth open wide. He would like to date, he said: “I want a girlfriend . . . to talk to.”

Brief, simple, and sincere, Tiquinho also spoke of death: “At first, I was afraid of dying. But I do not fear it anymore. I think that when I die, I will go to a beautiful place.”

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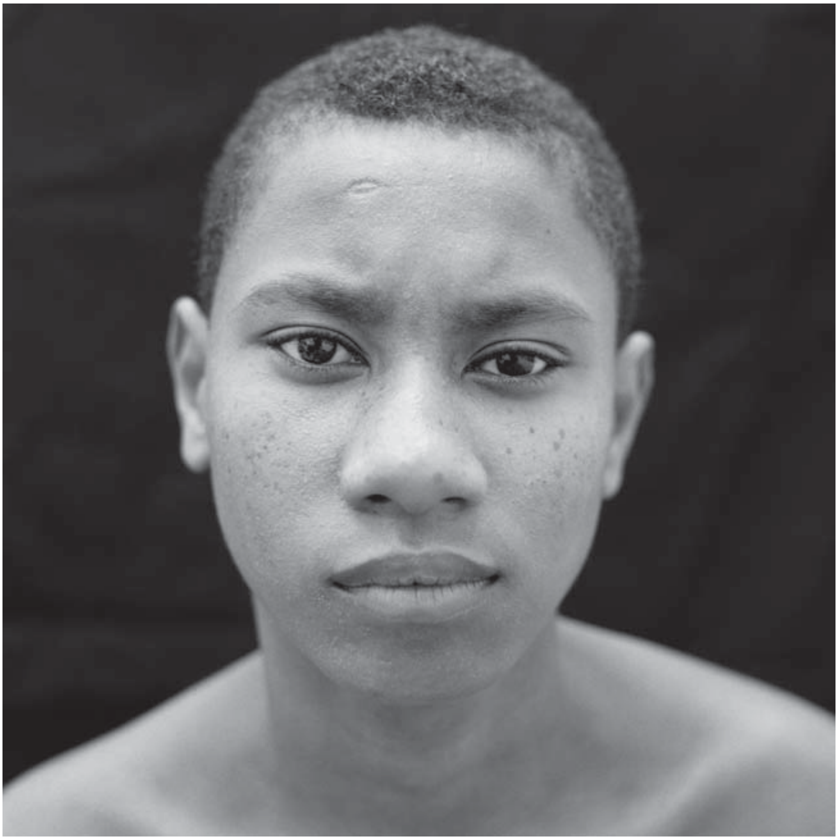
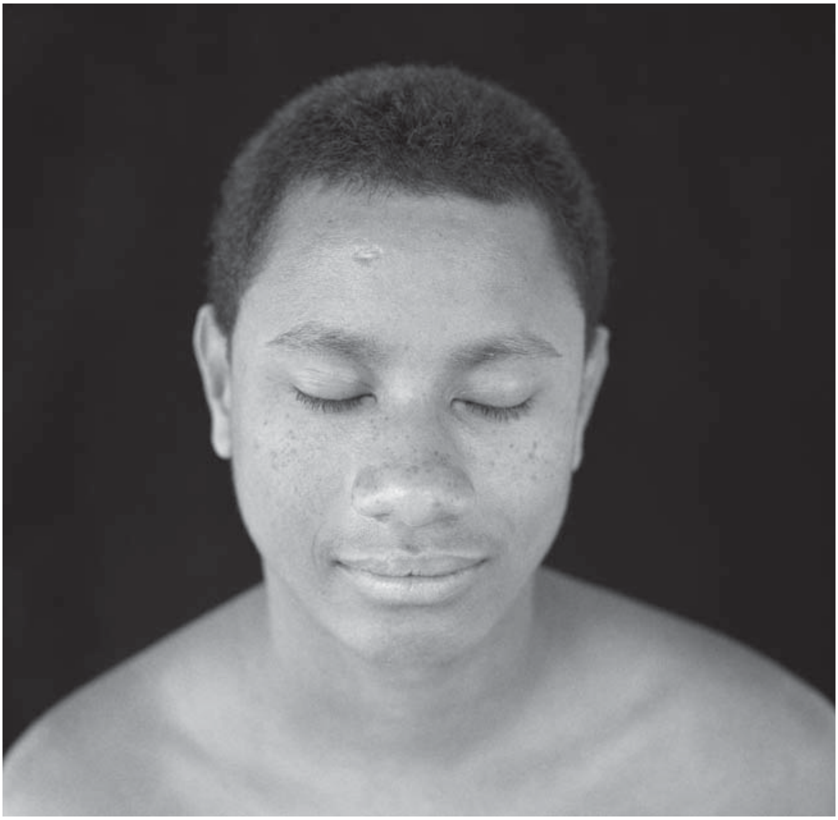
Tiquinho continued to live in Caasah. A born-again Christian, he had begun to participate actively in his church’s activities and was learning how to read and write. Caasah’s director did not believe that Tiquinho should spend his whole life there. She was making arrangements for Tiquinho to learn to self-medicate so that he could live with his family, who want him to return.



Tiquinho, 1997



Tiquinho, 2001

The Politics of Survival

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, alongside 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, technology, money, and survival. The ethnographer demarcates previously uncharted landscapes and tracks people moving through them. By addressing complicated transformations of institutions and lives in contexts of adversity, ethnography is uniquely qualified to confront and humanize the ways problems and policies are framed and interventions carried out.

Through unexpected political bodies such as Caasah, the question of social inclusion and health is worked out in different ways and levels. Operating within everyday violence and alongside AIDS therapies, there is an intense institutional and human maneuvering, a pulse of sorts. Treatment adherence is shaped in connectivity. Channels of communication linking the individual, the state, and the medical institution are constantly renegotiated, and newly found personal identities cannot be taken for granted.

I find Gilles Deleuze's insights on the "subjectivity of milieus" helpful to think through the maps people draw as they traverse old and new public formations. There is never a moment in which we are not plunged into actual milieus. The settings and situations we move through are made of qualities, substances, powers, and events. And the maps we make of these dynamic trajectories and of the intensities we experience in the process "are essential to psychic activity," the philosopher writes (1997). Such "constellations of affects" are especially relevant to individual and group becoming vis-à-vis AIDS therapies: "From one map to the next, it is not a matter of searching for an origin, but of evaluating *displacements*. It is no longer an unconscious of commemoration but one of mobilization, an unconscious whose objects take flight rather than remaining buried in the ground" (p. 63).

At the margins, both the institutional and the pharmacological matters surrounding AIDS treatment undergo considerable flux. And AIDS survivors themselves live in a state of flux, simultaneously acknowledging and disguising their condition while they participate in what I call *local economies of salvation*. Now using ARVs and living on their own, Caasah's former residents face the daily challenge of translating medical investments into social capital and wage-earning power. They live between moments, between spaces, scavenging for resources. Through all these circuits, subjectivity is refigured as a *will to live*. In turn, this interior force of life—articulated at the intersection of social death, biotechnology, and the unevenness of public services—also refigures the terms of care and citizenship.

The political economy of AIDS, spanning both national and international institutions, creates an environment within which individuals and local AIDS organizations are codependent and must recraft positions and possibilities with 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 constant 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 patients rarely become activists. Even as they search for employment, AIDS survivors work hard to remain eligible for whatever the state's paternalistic politics have made available—renewal of disability benefits, free bus vouchers, and additional medication at local health posts, for instance. Being adopted by a doctor and becoming a model patient (by complying with treatment in spite of a miserable situation) 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 for them.

This is not an inclusive form of care or of citizenship. Many are left out, saddled with other categorizations, such as drug addict, prostitute, beggar, or 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. To get that to which they are legally entitled, these individuals must not only identify themselves as belonging to the class of those served but also constantly seek out services. To retain services, furthermore, they must behave in particular ways. As a result, they largely remain part of the underground economy and constitute a hidden AIDS epidemic.

An ethnographic analysis of these linkages between macro-level policies, AIDS therapies, and care (or lack thereof) broadens our understanding of the forms that AIDS is taking and of what determines health outcomes among the most vulnerable. It concomitantly considers the organizational contexts that overdetermine inclusion and exclusion and the highly specific cultural contexts in which people assign value to their health status and lives. As life extension is now also possible for those who have been historically neglected, ethnography charts the trajectories that determine this mobilization. In noticing and documenting this *micro-politics of survival*, ethnography illuminates the paths through which people become the physicians of themselves and of their immediate worlds amid the growing tension between health as a public and a private good.[13]

By keeping these interrelated aspects in view—activism and political economy, pharmaceuticals and public health, population and individual, medicine and subjectivity—one organizes a more effective discussion of changing political cultures and ethics in an urgent time. *Will to Live* enters precisely into this sort of discussion. As I chart the trajectories leading to pharmaceutical forms of governance and personhood, I also attempt to open space for people who are missing in official data, policy decisions, and accounts. All this said, it is encouraging that with regard to AIDS, discussions about Brazil have shifted from social death to the maintenance and advance of a life-extending policy already well under way.