

7

Patient Value

João Biehl

“PHYSICALLY WELL YET...ECONOMICALLY DEAD”

“Today is another world,” Luis Cardoso told me as he looked at the portrait that photographer Torben Eskerod had made of him in March 1997 (fig. 7.1), when he was beginning to take AIDS therapies. It was now December 2001 and I was back in Caasah, a community-run AIDS-care facility in Salvador, the capital of the northeastern Brazilian state of Bahia. I wanted to know what had happened to the AIDS patients we had worked with in 1997. “One Luis has died, and another has emerged,” the thirty-six-year-old man continued. “My family and friends discriminated against me. For them, AIDS was a crime. A doctor sent me to Caasah.... Here people supported me. I got used to the antiretrovirals. Medication is me now.”

Caasah was also a changed institution. It was founded in 1992 when a group of homeless AIDS patients squatted in an abandoned hospital formerly run by the Red Cross. Soon after its founding, Caasah became a non-governmental organization (NGO) and began to receive funding from a World Bank loan disbursed through the Brazilian government. By the mid-1990s, the unruly patients in Caasah had been evicted, and a smaller group was undergoing an intense program of resocialization run by psychologists and nurses. “With time, we domesticated them,” recalled Celeste Gomes, Caasah’s director. “They had no knowledge whatsoever. We showed them the importance of using medication. Now they have this conscience.”

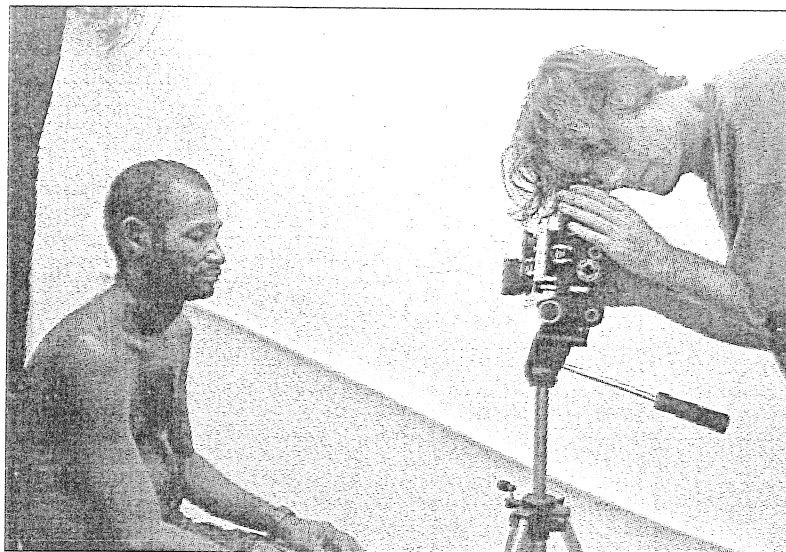


FIGURE 7.1

Luis and Torben at Caasah, 1997. Photograph by the author.

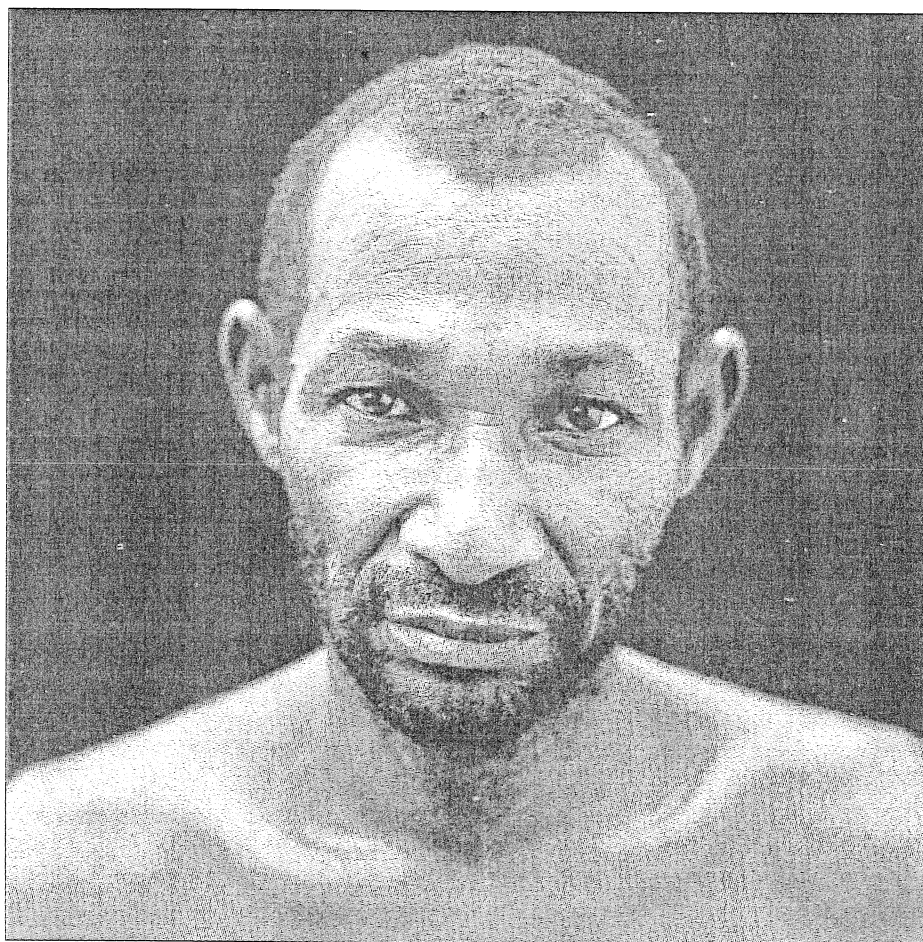


FIGURE 7.2

Luis, 1997. Photograph by Torben Eskerod.

Luis was one of the few who got that chance (fig. 7.2). He and his fellow “AIDS citizens” (as many in Caasah called themselves) knew all too well that inequalities of power, ranging from economic destitution to racial discrimination, determined who had access to what services. They had to take up a new patient identity, and this newly learned ability to “accumulate” health at Caasah was also a highly competitive enterprise.

With antiretroviral therapies (ARTs) more widely available, healthy residents like Luis had been asked to move out of Caasah. And in the past year, Caasah itself had moved to a new state-funded building. It had been redesigned as short-term recovery facility for patients sent by hospitals’ AIDS wards and a shelter for orphans with HIV. Maintaining the institution was a daily struggle, Celeste told me: “This is a beautiful building, but that’s all the state gave us. We owe more than \$1,000 to local pharmacies. Our patients come from the hospital with their ARTs but nothing else. No vitamins, no painkillers, no Bactrin to treat opportunistic infections.” Celeste remarked, “We now have this paradox that the poor AIDS patient is physically well yet he is economically dead.” Disturbingly, as I would find out, the state AIDS unit and Caasah made no systematic effort to track patients and their treatments once they left.

SUBJECTS OF RIGHTS AND INTERESTS

Via pharmaceuticals and at the mercy of a volatile economy, Caasah’s patient-citizens live in flux. Like millions of other poor AIDS patients worldwide who now have access to treatment, they struggle to move out of the stream of history and into a technologically extended life (Fassin 2007; Hunter 2010; McKay 2012; Nguyen 2010; Reynolds Whyte et al. in press). As they scavenge for resources and care, their lives reveal desperate and extraordinary efforts to swerve around and exceed constraints of all kinds.

As these new subjects of biomedical rights try to undo social death, they also express world-altering desires. Luis was happy to show me the photograph of Davi, the three-year-old boy he had informally adopted. “His parents died of AIDS. He was living here in Caasah. I now pay his grandma to care for him. All expenses are on me. I love him.” The disability pension and salary he earned as Caasah’s office assistant enabled Luis to pay his bills and save for the home he dreamed of owning.

AIDS therapies have opened up a space that did not exist before. But they alone cannot explain everything that has happened to Luis. This chapter is about Luis and the social fields that the new people of AIDS invent and live in. I am particularly concerned with how subjects of biomedical rights (as in the case of Brazil’s AIDS citizens) struggle to become

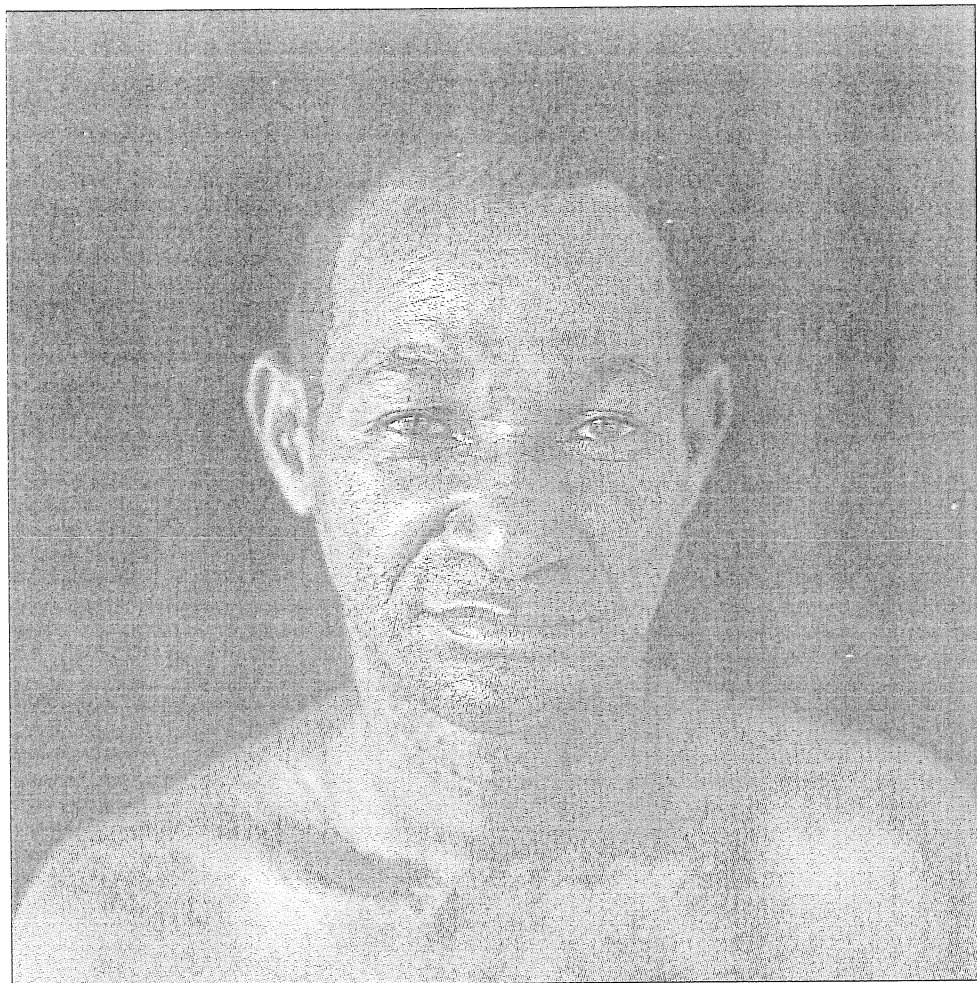


FIGURE 7.3

Luis, 2001. Photograph by Torben Eskerod.

Homo economicus—the values they espouse and the ways they speak of state and society. As I show throughout the chapter, the world-altering desires and doings of these ambiguous political subjects upset probabilities, bias estimates, and expand the limits of what can be known and acted on in the new world/market of global health (fig. 7.3).

Caasah's initial collective arrangement replaced the absent family and enabled Luis to access medical and psychological care. "Here I stopped blaming others for what was happening to me. Self-pity and hatred keep you imprisoned, don't let you live the present. I learned that the AIDS patient has the right to struggle for a future like any other human being. I always look first at what is up to me to do. I must have this conscience...to have to take food and medication and to sleep at the right time, to always be alert to my symptoms and to the weather, to schedule my medical appointments. I am the effect of this responsibility." Treatment regularity occasioned a

previously unknown gratification. Luis said, "I gained another body. But it is a mistake to think that one can put the guards down."

This novel engagement with technology is lifelong and involves constantly challenging and interrogating the self. It requires personal virtue, Luis insists, a new way of claiming actuality and existing beyond immediacy. "If one wants to have a real life one must make medication a routine and...know what is good for oneself, beyond the moment. The world presents all possible paths. It is a school in getting lost. But it is up to me to take life forward. I know that beyond the immediate pleasure of a drug or of alcohol, there are grave consequences. So I chose to do what is best for me, and I don't counsel anyone to take the easiest route."

Luis is an amazing person: hardworking, wise, witty, and masterful at moral discourse. He spoke of a new moral economy (Fassin 2008) organized around AIDS therapies. And he himself was the dominant human form that emerged from this economy. "I face my problem. I take advantage of the help I get. I struggle to live." He was indeed the representative of a new medical collective and subject position, and his discourse conveyed the present-day forms and limits of society and state. "I have nothing to do with society," he said. "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."

The new Luis spoke as if the paradigm of an activist civil society was vanishing and, in its wake, a conjoined subject of rights/interests had emerged in relation to medical technology. "People fought a lot, and we are now a country in which the AIDS therapies have not been missing. This is the good aspect of the state. The rest is for me to do."

Luis had harsh words for those who threw medication away: "It's a crime." A crime against the state and the person himself, Luis reasoned. "The government is paying a lot for medication. To keep the person hospitalized would be even more expensive. People don't sell the antiretrovirals, for no one would buy them. Many people with AIDS already gave me their drugs, and I brought them to Caasah. Tell me, what is the point of dying in a hospital bed? I must follow the medication regimen rightly."

Luis made adherence to treatment seem too easy. As much as I admired his resilience and uplifting presence, I also found his righteousness quite disturbing. For him, individual conscience was the foundation of a healthy existence, and mourning a loss, any kind of loss, was a defect to be overcome. Moreover, his overemphasis on individual responsibility was self-serving. It clearly reflected Caasah's house-of-passage *modus operandi* and, more broadly, the hegemonic discourse that one has to be evermore

self-conscious, in control of oneself, upbeat, and forward looking. The institutional and interpersonal forces that threw Luis into action in the first place were by and large absent from his life-extending account, particularly as he spoke of noncompliant *marginais* (marginals). It was evident from his recollection of the recent past that without belonging to Caasah, he would not have benefited as he had from the AIDS therapies and that he kept harnessing strength from being the object of regular public attention (as the “good” AIDS patient, volunteer, and peer educator).

Yet, in Luis’s technocratic moral discourse, social abandonment exists in a vicious cycle with self-created risk and the possibility of self-destruction. His pharmaceutical subjectification had indeed led to salutary effects, yet it was built upon the exclusion of those who cannot conform and who remain at the periphery of this local economy of salvation. “It is not a matter of getting the street patients help, for they already have medication. They use their social condition as an excuse to keep their habits.... It is a question of self-destruction. As I see it, these people are more for death than for life. But I also know many people who struggle to live and to earn their money honestly and don’t surrender.... It is your mind that makes the difference.”

NEW FORMS OF THEORIZING AND RECONSTRUCTING WORLDS

Antiretroviral treatment rollouts are matters of intense negotiation; their local realizations are shaped by contingency and uncertainty. As I show throughout this chapter, such realizations encode diverse economic and political interests, as well as the anxieties and desires of groups and individuals. Drawing from my long-term study of the Brazilian therapeutic response to AIDS, I explore the limits of the vertical-technical-fix approach in global health and the feasibility of people-centered initiatives. Broadly speaking, I am concerned with (1) the arts of government that accompany pharmaceutical globalization, (2) the remaking of people as market segments (specifically, therapeutic markets), and (3) the articulation of para-infrastructures for everyday living.

Several questions guide this chapter: When and under what conditions are marginalized people accounted for as population subjects in new biomedical regimes? How do social projects (such as Caasah) become integral to novel state–market formations (such as the AIDS policy)? In which ways can patient-citizens draw resources from social projects and governments as they negotiate the vagaries of the market and survival? How can anthropology map these precarious para-infrastructures and think through the ambiguous political subjectivities that crystallize amid the blurring of

distinctions among populations, market segments, target audiences, and collective objects of intervention or disregard?

Ethnographic evidence consistently dies within dominant frames of knowledge production in global health (Biehl and Petryna in press). People are put into preconceived molds, and the multiplicity of realities and lines of flight that ethnography makes available has nowhere to live in the counting of drugs delivered, in the dire and faulty statistics of mortality, or in the biased selectivity of randomized experiments. Moreover, policy and popular accounts tend to cast people as helpless victims, overdetermined by environment, history, and power, or as miraculous survivors who bear witness to the success of external aid. Details are suspended. Broken infrastructures, rifts that deepen, and larger political economies in which these lives unravel seem peripheral to both analysis and activism. But in our anthropological works, we must continue to challenge orthodoxies of all kinds and seek original ways to communicate the categories that are significant in human experience—which the powers that be dismiss as anecdotal, nongeneralizable, and inherently impractical—to the worlds of science, policy, jurisprudence, and caregiving. If this kind of engagement leads to the subtraction of quick-fix theories and policies and to the addition of new forms of theorizing and reconstructing worlds, so much the better.

OPEN-SOURCE ANARCHY

Brazil accounts for 36 to 57 percent of all HIV/AIDS cases in Latin America.¹ An estimated 630,000 Brazilians in the fifteen to forty-nine age group are living with HIV/AIDS. The prevalence of HIV infection in the population at large has remained stable at around 0.6 percent since 2004; among women, the rate of infection is 0.4 percent and among men, 0.8 percent (Szwarcwald et al. 2008). But social epidemiological studies show considerable heterogeneity in HIV infection rates, with large numbers infected among vulnerable groups such as men who have sex with men, commercial sex workers, and injecting drug users. Brazil is indeed known for its stark socioeconomic inequalities and for its persistent development challenges. Yet, against all odds, Brazil invented a public way of treating AIDS.

In late 1996, groundbreaking legislation guaranteed universal access to antiretroviral therapy. This policy resulted from potent rights-based social mobilization, legal activism, and novel public-private partnerships. The democratic constitution of 1988 granted the right to health to all citizens and mandated the creation of a national health-care system—AIDS activists were the first group to effectively equate this right to access to

medicines. Some two hundred thousand Brazilians currently take antiretroviral therapies paid for by the government. The government managed to reduce treatment costs by promoting the production of generics and also negotiated substantial price reductions from pharmaceutical companies.

According to the Health Ministry, both AIDS mortality and the use of AIDS-related hospital services have fallen by more than 50 percent. Perhaps even more impressive is the steep decline in mortality during the first year after diagnosis, signifying the transformation of HIV/AIDS from an acute to a chronic disease. Brazil's bold, multi-actor, large-scale therapeutic response to AIDS has made history. The country empirically challenged the economic and medical orthodoxies that treating AIDS in resource-poor settings was infeasible and that poor patients could not adhere to complex drug regimens—as a result, Brazil has been a leader in the struggle to universalize access to AIDS therapies.

Yet, I wondered, what would be the effects of the universal treatment policy on the country's poorest and most marginalized citizens, among whom HIV/AIDS is spreading most rapidly? How would people such as Luis and Salvador's "street patients" transform a death sentence into a chronic disease? What social innovation could make such medical transformation possible?

For more than ten years, I have explored the impact of the AIDS treatment rollout on Brazil's government, its health systems, and individual lives. I have interviewed policy-makers and health professionals and carried out a long-term study of marginalized AIDS patients in Salvador. In charting the lives of poor patients before and after they had access to ARTs, I (Biehl 2007) wanted to open a window into the real-life outcomes of novel national, international, and corporate policies.

In my ethnographic work, I also engaged nongovernmental and pharmaceutical communities as they took up the call for responsibility and care in the face of AIDS. Until recently, global health initiatives were the domain of states through the coordination of specialized international bodies such as the World Health Organization (WHO). In the past decade, however, a complex matrix of partnerships (state and nonstate actors that include philanthropic organizations, nongovernmental organizations, and pharmaceutical industries) has arisen and is shaping health interventions worldwide, increasingly under the framework of security—the field of global AIDS treatment is paradigmatic of this trend.

Public-private partnerships in global health come in multiple forms, and they have diverse interests, ranging from the Bill & Melinda Gates Foundation to corporate drug donation programs to PEPFAR (the US

President's Emergency Plan for AIDS Relief) to myriad small and hopeful pilot projects. These various actors set goals and new norms for institutional action and sometimes fill voids in places where national systems and markets are failing to address public health needs or have been absent altogether. Whatever ideological differences exist across corporate, activist, and state public health agendas, the imperatives of "treatment access" and "saving lives" appear to reconcile these differences and fold them into an ethos of collective responsibility in the face of "crisis." Arguably, players can become impervious to critique as they point to crises and dire statistics and their essential duty to act on health in the name of humanitarian reason or as an instrument of economic development, diplomacy, or national security (Fassin 2011; Fidler 2007; Sachs 2005a; Singer 2009). We are left with an "open-source anarchy" around global health problems (Fidler 2008)—a policy space in which new strategies, rules, distributive schemes, and practical ethics of health care are being assembled, experimented with, and improvised by a wide array of deeply unequal stakeholders.

So far, few if any institutions are in place to monitor this burgeoning and somewhat disordered "public goods" field (Adams, Novotny, and Leslie 2008; Biehl 2008; Samsky 2012). In practice, the interests and concerns of donors, not recipients, tend to predominate, and the operations of international organizations tend to reinforce existing and unequal power relations between countries (Banerjee 2005, 2007; Epstein 2007; Ferguson 2006; Ramiah and Reich 2005). Moreover, initiatives tend to be disease specific and are increasingly dominated by scientifically based measures of evaluation revolving around natural experiments, randomized controlled trials, statistical significance, and cost-effectiveness (Duflo, Glennerster, and Kremer 2008; Todd and Wolpin 2006)—a technical rhetoric aligned with the demand of funding organizations for technical solutions. Traditional public health initiatives are now categorized as "nonscience," and this "scientific preoccupation" tends to overlook the on-the-ground dynamics of programs—assuming that other settings are replete with distinct institutions, practices, and rationalities—not to mention the more intractable failures in the infrastructure of receiving countries (Adams *in press*; Deaton 2010).

Indeed, much is sidestepped and remains unaccounted for in this global form of governance and medical experimentality (Petryna 2009; Whitmarsh 2008). Magic bullet approaches have been the norm in international health for decades now—that is, the delivery of health technologies (usually, new drugs or devices) that target one specific disease regardless of myriad social, political, and economic factors that influence outcomes.

A growing number of social scientists and health policy advocates has been cautioning, however, that a narrow focus on technology delivery, the basic science of disease, and patient compliance, as important as they are, is inadequate by itself. They argue that we need to better attend to a wide array of structural and social determinants of health and find ways of integrating them into delivery and care (Farmer 2004, 2010; Freedman 2005; Hahn and Inhorn 2008; Singer and Hodge 2010). Moreover, extreme inequalities in the distribution of risk and disease remain structured into the current international order, and unintended consequences are unleashed by even the most carefully designed interventions.

What happens concretely when new treatments are introduced into epidemiologically diverse and variable social worlds? How is care organized by providers and state and nonstate institutions, and by what struggles and mechanisms is care acquired—or not—by the people who desperately need it?

LOCAL ECONOMIES OF SALVATION

The ethnography of AIDS after the introduction of antiretroviral therapies illuminates processes of individual and group becoming, as Luis suggests, taking place through medicines and multiple sites, relations, and intensities—fields of immanence. It is within this circuitry, as it unequally determines life chances, that AIDS survivors articulate their plastic power (instead of a given truth or life form) and invent ties and temporary medical collectives that enable a domesticity and health—a plateau of sorts—to live in and by.

The day after I talked to Luis at Caasah in December 2001, he joined me on a visit to Rose. She had been a founding member of Caasah and, like Luis, had also been asked to move out as she “gained body.” I would have never found Rose’s place on my own. No traffic signs guide you through these labyrinthine favelas-turned-commercial-districts. Houses and informal businesses blur in an unplanned and overcrowded way. Luis did not use the words right or left, and after missing a few exits and having to make some dangerous turnarounds, we finally reached the bumpy highway that connects southern and northern Brazil. Five miles north, we turned right onto an unpaved road and into the heart of Salvador’s misery: the Cajazeiras district.

Rose was waiting for us. “It’s a poor shack, but it is mine.” She introduced us to Jessica, her one-year-old daughter, and Ricardo, her eleven-year-old son, who had previously been under the care of “Professor” Carlos, the man who had been Caasah’s head nurse for several years until health authorities found out that that he had forged his nursing diploma (he was

now Caasah's operations manager). At any rate, Rose's kids kept watching television as we sat to talk.

She immediately made fun of her new hairdo. "It's modern. I straighten it and put some color in it. Men will be knocking at my door.... For someone who passed through hell, I am in good shape. I am strong and conscious, right, Luis?"

Tearful, she recollected the death of her partner Jorge from AIDS-related diseases a few months before Jessica was born. "He wanted this child so much." Rose knew that Jessica's HIV-positive status could still change. "She has never been ill, and we hope for the best. This is how I lead my life...always struggling to pay the bills, raising my children, for I am mother and father."

Rose had given birth to another daughter in 1993 in Caasah. Rose gave her up for adoption to Naiara, Caasah's associate director. I also learned that Ricardo's father lived in the streets and also had AIDS—a word Rose did not utter.

"Life continues. When one has the 'girl' [*menina*], one must have the responsibility. I can do everything, but within my limits. I am not a fanatic patient. There are people who think about *it* twenty-four hours a day and who live in hospitals. I live a normal life. I know to have fun, too." As Rose used the word *menina* and the pronoun *it* to refer to AIDS, she gesticulated to convey that she was talking in code because of the kids and the neighbors. "They don't know I have the *menina*. It's tough to go about life without *it*, and if you have *it*, oh Lord, no one wants anything to do with you."

"The first time we met in Caasah—it was 1995, right?—we were all losers there," Rose continued. "If I look back, I consider myself victorious. I am thankful to the government for the medication and to Dr. Nanci [her physician]. She is a blessing, a mother to me. I never had another doctor, and I never had this problem of having to change treatment. People fight to have Dr. Nanci as their doctor. We are siblings in Christ and in doctor, right, Luis? When the antiretrovirals first came in, we were among those she gave priority."

Like Luis, Rose spoke of being medically conscious and responsible. Yet, in her account, new life was anchored in the experience of being saved by Caasah. Like most poor AIDS patients, Rose had experienced cruel forms of abandonment and self-abuse and had no family, no one to count on. "I had no support. I was lost in the world. The world was the only school I had, and it ended in what it did." Death by AIDS, she meant, a destiny she escaped. "We were lucky to get disability pension before the medication. We are the founders of the old institution. Caasah was my salvation. The

majority who now applies for disability does not get it. We had everything done for us, food, medical appointment.... That routine helped."

To adhere to ARTs, to make a child, and to take on maternity/paternity in such vulnerable and precarious conditions—"life is on a hanging thread"—was already the effect of something else, evidence that a change had taken place. Caasah made it possible for Rose and other socially dead subjects to reconstruct themselves from ashes. In her account, "salvation" had to do with distancing oneself from and elaborating upon losses and failures, with finding a place for death other than in one's body. "One was the mirror of the Other. This proximity and constant interaction made one reflect on what had passed." In this intervening grassroots space—which redefined what family is—a discourse of morbidity was channeled into agency and labor vis-à-vis the newly available medical technologies.

Caasah remained a foundational reference (material and symbolic) to the AIDS- and class-defying, breadwinning mother Rose had become. "I know that they have financial difficulties there. It is a big operation. And they have the children now. But I am glad I can count on them. When Celeste and Naiara see that I have a serious problem, they say, 'Come here and we will see what we can do.'" Rose confided that Professor Carlos, informally, kept playing nurse to her. "He helps me a great deal. I don't care what people say about that creature.... Whenever I need a drug I cannot buy or I have a wound that won't heal, I can count on him."

She complained bitterly about the lack of medicines for opportunistic diseases in the hospital and local health post and told me how she herself had become a proxy-physician/pharmacist, recycling available medications through trial and error. "The basic pharmacy program and health post is just facade. A few weeks ago, Jessica got this horrible scabies. I couldn't get a specialist in this end of the world. So I had to tell Dr. Nanci about it. She gave me a prescription but had no samples. The medication was too expensive. I couldn't buy it. Carlos had given me a medication. So I used it in Jessica. Thank God, it worked."

Rose's powerful discourse of salvation from the world, from herself, and from social AIDS—"I am a new creature. You can write my story"—was matched by an equally powerful account of the ways she was able to establish and sustain transference with people standing for state and medical institutions and thus realize her new life. The actions she microscopically alluded to reflected long-lasting social and subjective forms based on *apa-drinhamento*—the practice of godfathering, as revealed by the canonical works of Gilberto Freyre (1987) and Sergio Buarque de Holanda (1956). Pragmatically, to have one's child adopted by someone powerful greatly

helps one to traverse institutions and to access goods. This engineered kinship stands for and does the welfare work of the community and neighborhood and, ultimately, also makes the vision of social mobility possible.

Rose went to the kitchen to brew coffee. Quite poignantly, she served us *cafezinho* on a tray. She was proud of her well-cared-for home, urbane manners, and children—"The boy is my right arm"—and she was always captioning her moves. "Who would have imagined that Rose, from the Pelourinho, would be giving interviews, telling the professor from the United States what life is all about, huh? 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."

Rose also made it evident that she was expecting some financial aid at the end of our session. "Any aid is welcome, my brother. You know that I limp, from those mad times [intravenous drug use]. I need help to buy Voltaren [a painkiller]. The other day, the pharmacist sold me five tablets. I didn't have enough money to buy the whole box. And I couldn't buy meat that week. It's not easy."

HOMO ECONOMICUS AND THE INTENSITY OF SURVIVAL

We have no easy way of understanding how a technologically prolonged life may be achieved in Brazil or in the growing number of other poor countries where AIDS is finally being treated through an unprecedented array of public- and private-sector initiatives. More than 25 million have died of AIDS to date, and an estimated 33 million people are living with HIV worldwide, about two-thirds in sub-Saharan Africa. Some 15 million people are in need of antiretroviral therapy. The battle for access has been hard fought, and nearly 6.6 million are now on treatment in low- and middle-income countries.²

Global AIDS treatment rollouts rightly open the door to medicinal access, but they also exemplify the inadequacies of a magic bullet approach to health care. Disease is never only one thing, and medicines are ancillary to care and well-being over time. Not money or medicine or a sophisticated pilot project can alone guarantee success. Healing, after all, is a multifaceted concept, and *healing* is no more synonymous with *treatment* than *treatment* is with *medicines*. Statistical strategies and profit motives hover above, by and large missing the interpersonal networks that link patients, doctors, and governments and are especially important in resource-poor settings where clinical infrastructures are not improving. AIDS deaths and HIV infections continue to increase among the destitute. An estimated 2.6 million people become newly infected each year. For them, HIV/AIDS is one tragedy among many others.³

These realities are not reducible to the critical theories we bring to the field. Numerous anthropologists have been using Michel Foucault's (1980, 2007) formulation of biopower—how the naturalness of population became central to Western techniques and conducts of government—to assess emerging assemblages of technology, medicine, and governance, particularly in the face of HIV/AIDS (Comaroff 2007; Fassin 2007; Nguyen 2010; Robins 2006). Yet, the Foucauldian biopolitical maxim *making live and letting die* deserves deeper probing because it might assume transcendent forms of power, along with homogeneous people and overly normalized populations (Biehl 2005; Biehl and Locke 2010; Biehl and Moran-Thomas 2009; Deleuze 2006). It has to be tested against the intense political-economic-experiential fields that Luis, Rose, and millions of other poor AIDS patients now on ARTs traverse in their quest for survival. Here the absoluteness of neoliberal principles in health-care delivery goes hand in hand with a surprisingly absolute juridical subject of rights, and we also witness the power of biotechnology to remake human and social worlds, opening up new spaces of contestation, resistance, and ethical problematization.

As I have been arguing, 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 to make ARTs universally available to its citizens and also to open up new market possibilities for that industry. The policy's sustainability has to be constantly negotiated in the marketplace, and one unintended consequence of the AIDS treatment ramp-up has been the consolidation of a model of public health centered on pharmaceutical access. This intervention gains social and medical significance by being incorporated into infrastructures of care that are, themselves, being reshaped by state and market restructuring.

In 1978–1979 lectures at the Collège de France, Foucault (2008:2) aimed to retrace “the rationalization of governmental practice in the exercise of political sovereignty” from the principle of right and law to an age of critical governmental reason. “Political economy made it possible to ensure the self-limitation of governmental reason” (2008:13), and liberalism tells the government, “I accept, wish, plan, and calculate that all this should be left alone” (2008:20). Interestingly, Foucault (2008:19) puts a pause on the analytics of biopower (particularly on the power/knowledge apparatus that marks that which does not in reality exist—“madness, disease, delinquency, sexuality, et cetera”—and submits it to “the division between true and false”), which was supposed to be fully spelled out in these lectures. We can adequately analyze biopolitics only when we understand the economic

truth within governmental reason, he stated. "Only when we know what this governmental regime called liberalism was, will we be able to grasp what biopolitics is" (2008:22).

After all, the market is the "site of veridiction—falsification for governmental practice" (Foucault 2008:32). In this reality, the possibility of the collective good as an object of governance or as an interest guiding individual lives is excluded. The imperative to pursue economic self-interest without interference from the government means that *H. economicus* cannot become aware of the ways in which he functions to support the advantages of others within a system. This situation implies a departure from the biopolitical model of governance in which population well-being is the object of administration and regulation. Foucault actually ends the *Lectures* with the surprising notion of civil society as a "transactional reality." Because there is "no localization, no territoriality, no particular grouping in the total space of the market" (2008:301), it is "the idea of society which permits the development of a technology of government based on the principle that it is already in itself 'too much'" (2008:319). Civil society works as "the medium of the economic bond" of subjects of interest and is "a permanent matrix of political power" (2008:303). This concept-work unleashes a myriad of questions about present-day crises in the apparatuses of governmentality and the concrete actuality of liberalism among us and how we apply a liberal politics to ourselves today (Berlant 2011; Biehl and McKay 2012; Povinelli 2011).

The travails of Caasah's AIDS survivors introduce us to contemporary linkages that, somewhat and for some time, connect the rights of people with the utilitarian calculus that presumes independent, rational choice-making economic subjects. Traversing worlds of risk and scarcity, constrained without being totally overdetermined, people create small and fleeting spaces, through and beyond classifications and apparatuses of governance and control, in which to perform a kind of *life bricolage* with the limited choices and materials at hand (including being the subjects of rights and pharmaceutical treatments made available by state and nonstate actors). Scholars and policy-makers are challenged to respect and to render publicly intelligible, without reduction, the angst, uncertainty, travails, and passion for the possible that people like Luis and Rose, amid lifesaving interventions, are left to resolve by themselves and, too often, at the expense of others.

When I returned to Salvador in August 2000, I worked with the roughly thirty homeless patients under the care of a nurse called dona Conceição (Biehl 2007). They were living on a concrete platform adjacent to the city's

main soccer stadium. Many looked undernourished, had skin lesions, and complained of flu-like symptoms. But Carisvaldo philosophized, "We push life forward anyway." Several said that they had begun picking up free anti-retrovirals at the hospitals but that they had stopped using them. Roberto declared, "Medication alone will not solve anything." His friend Jair said that he did not believe in the efficacy of the drugs. "My medicine is food. beans in my belly." A culture of "compliance" was far from here.

At the end of that week, I went to Brasília, where I met with Dr. Paulo Teixeira, then coordinator of the National AIDS Program. "The success of the Brazilian AIDS policy is a consequence of the activism of affected communities, health professionals, and government," he told me. Two years later, I would hear a similar explanation from Fernando Henrique Cardoso, Brazil's former president: "Brazil's response to AIDS is a microcosm of a new state-society partnership," he told me.

The AIDS policy emerged against the background of neoliberalization, and the politicians involved with it were consciously articulating a market concept of society. For Cardoso, citizens are consumers who have "interests" rather than "needs." In the words of economist and former health minister José Serra, whom I also interviewed in 2003, "the government ends up responding to society's pressure. If TB had a fifth of the kind of social mobilization AIDS has, the problem would be solved. So it is a problem of society itself." In this rendering, the government does not actively search out particular problems or areas of need to attend to—that is the work of mobilized interest groups. In practice, activism has enhanced the administrative capacity of the reforming state.

Luis's and Rose's trajectories, like those of many others, show how empowering pharmaceutical access can be but also how much additional effort is required to transform medicines that are "accessible" into medicines that are effective in the everyday lives of poverty-stricken patients. A vertical, top-down, mass campaign against a disease, although valuable, leaves unaddressed the social realities that co-construct health outcomes. Health policies need to be directed at *people*, not simply disease.

ANTHROPOLOGY OF THE MEANTIME

For more than ten years, I have chronicled life in and out of Caasah. By repeatedly returning to the field, one begins to grasp what happens in the *meantime*—and I like to think of this work as a study of 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 how policies unfold over time—and the literalness of becoming, as AIDS survivors transition from patienthood back into personhood. I say *becoming*, for we have a responsibility to think of life in terms of both limits and crossroads, where technologies, interpersonal relations, and imagination can sometimes, against all odds, propel unexpected futures (Biehl and Locke 2010).

AIDS therapies are now embedded in landscapes of misery, and hundreds of grassroots services have helped to make AIDS a chronic disease even among the poorest in Brazil and beyond. These services are 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 anthropologist Vinh-Kim Nguyen [2005:126] has framed the politics of antiretroviral globalism). Based on my study of Caasah, I am arguing that the question of accountability has been displaced from government institutions and that 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 interpersonal dynamics 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. 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*.

The anthropologist, upholding the rights of micro-analysis, brings into view the fields that people, in all their ambiguity, invent and live by. Such fields of action and significance—leaking out on all sides—are mediated by power and knowledge, and they are also animated by claims to basic rights *and* desires, as Rose affirms. It is not enough to simply observe that complicated new configurations of global, political, technical, and biological (and other) segments exist or are the temporary norm. We must attend to the ways these configurations are constantly constructed, undone and redone by the desires and becomings of actual people caught up in the messiness, the desperation and aspiration, of life in idiosyncratic milieus. Nor is ours necessarily a choice between primarily “global assemblages” (Collier and Ong 2005) and principally local “splinters” of a “world in pieces” (Geertz 2000). At the horizon of local dramas, in the course of each event, in the ups, downs, and arounds of each individual life, we can see the reflection of larger systems in the making (or unmaking). And in making public these singular fields—always on the verge of disappearing—the anthropologist still allows for larger structural processes and institutional idiosyncrasies to

become visible and their true impact known. Thus, what we find is a movement from collective epidemic to personalized disease; from public health to the pharmaceuticalization of health care; from governmental distance to the industrialization of the nongovernmental sector and to a privatized politics of survival.

Critical questions abound: Can we think of the biopolitical as a multi-scale battle over the utility of government by private and public stakeholders? Does the “futility” of the biopolitical rehabilitation of surplus poor and diseased subjects (as in Luis’s rendering of death-driven street patients) speak to the waning of civil society as a viable “transactional reality” for social justice? Might the subject of rights and the economic subject actually be included or excluded according to shared or similar logics, practices, technologies, and knowledges? And might inclusion in the name of rights, as we see in the world of global health and humanitarian interventions, be a key means by which one becomes part of a market segment? Is the market, then, what must be and is ultimately always produced both in government and by people?

PATIENT VALUE

The most prominent proponent of an approach that innovatively blends vertical technological intervention with a horizontal focus on making health systems work is anthropologist Paul E. Farmer (2001, 2004, 2010). Farmer and Partners In Health, the organization he cofounded with Jim Y. Kim, are especially interested in understanding diseases as nexuses of biological and social determinants of health, as well as revealing the structural conditions that make diseases possible and perpetuate them. Partners In Health works with local communities in Haiti, Boston, Peru, and now Rwanda. Each local clinic becomes a nexus of care, integrating HIV/AIDS treatment and prevention activities, for example, while also attempting to address coinfections and the new medical problems AIDS patients face as they age. Accounting for individual trajectories and staying with patients through the progression of the disease and treatment (the work of paid *accompagnateurs*) is considered as important as tackling the economic and social factors that impact their families and mitigating the demise of clinical infrastructures.

As part of his push for the best available care for the world’s neediest people, Farmer (2008) urges the elimination of superficial metrics of “cost-effectiveness” that focus on particular interventions and shortsighted measurements of profits. His argument, however, is not a call to reject economics (in fact, it is this discipline’s pragmatism that Farmer says others should

emulate), but instead to incorporate different values and temporalities into the evaluation of initiatives that affect public health. In this way, Farmer is able to reject structural adjustment programs that demand the elimination of health expenditures in the name of economic development (increases in gross domestic product per capita that seldom make their way back to those most afflicted by austerity measures and budget cuts), which result in sicker populations with even slimmer chances of finding care in now crumbling public health systems (Pfeiffer and Chapman 2010). He also rejects the limitations of wraparound services imposed by cost-effectiveness benchmarks that fail to take into consideration the longer-term and far-reaching social, economic, and medical benefits of providing such services.

In an interesting convergence, Farmer and Kim have been collaborating with business scholar Michael E. Porter on the articulation of a science of global health delivery (Kim and Porter n.d.).⁴ According to Porter (2009; Porter and Teisberg 2006), current systems of health-care delivery in the United States and globally rely on very narrow measurements of efficacy that concentrate exclusively on the intervention level and can only assess discrete preventative steps, drugs, or services. “Global health is stuck in an access and volume mindset, rather than focusing on the value delivered to patients” (Kim and Porter n.d.:4). For patient value to be achieved, interventions should be informed by a strategic framework that would orient the design and operation of health delivery systems as a whole instead of the discrete-component approach currently in use.

A more holistic understanding of health is called for, and interventions should be evaluated at the level of medical conditions. “the set of interrelated patient medical circumstances involving the full disease cycle” (Kim and Porter n.d.:11). In order to create such a framework, numerous and diverse disciplines (including anthropology) must be engaged, each producing knowledge at a different scale and perspective that can be integrated into a workable knowledge regarding the complexities of the context and content of interventions. At stake in the process is also changing the epistemic framework that informs donors’ priorities and funding decisions, as well as global health evaluation schemes.

Meanwhile, the magic bullet approach, with its focus on drug delivery and supply chain management, stretches far beyond the antiretroviral rollout. Many tropical diseases have also been subject to blanket treatment approaches, including childhood malaria, river blindness, and parasitic infections. But as historians of the fight against syphilis and malaria remind us, eradication is an elusive target (Brandt 1987; Cueto 2007). Just

as medical know-how, international political dynamics, and social realities change, so are biological systems in flux—bugs grow resistant, new infections appear. A more complex model of this flux of people–disease–policy and market dynamics is needed and requires innovative partnerships and methods as suggested by Farmer, Kim, and Porter.

Consider the widely cited study by economists Michael Kremer and Edward Miguel on curing worm infections in rural Kenya. Kremer and Miguel found that treating Kenyan schoolchildren with extremely cheap deworming medication increased their school attendance by some 10 percent. A *New York Times* op-ed heralded the study as “landmark” (Kristof 2007): with just a bit of cheap medication, poor countries could increase school attendance by leaps and bounds. Given the affordability and stunning success of the treatment, many commentators suspected that families who had not benefited from treatment during the study would very happily adopt this new technology.

But Kremer and Miguel (2007) then observed a puzzling turn of events when they followed a group of families outside the original study (their ethnographic turn) after the trial had ended. Among these families, those who were friendly with families in the treatment group were *less* likely to treat their children than those who were friendly with families in the control group. They were also less likely to deem the medication effective at improving health. If deworming medicine is the panacea for anemia and school truancy, then why were better-informed families not treating their children?

Here again we have a case in which the interpersonal relations and needs of people on the ground elude controlled studies. With their strict methodological imperatives, global health scholars, experts, and planners often sacrifice existing ethnographic evidence or counterknowledge as experiments and interventions (ever more closely linked) unfold—at the expense of better understanding and, ultimately, more meaningful and long-lasting outcomes.

The question of how to bring local communities into the very design and implementation of feasible (rather than technology-enamored) interventions is a continuous challenge. With international and national health policy success being largely reframed in terms of providing and counting the newest technology delivered, what space remains for the development of low-tech or nontech solutions (such as the provision of clean water) and the strengthening of public health systems and preventative measures that could prove more sustainable—and ultimately more humane?

FRAGILE ISLANDS OF HOSPITALITY

"If you look carefully, nothing has changed," a tired Celeste told me during my last visit to Caasah in August 2005. Caasah was still the only place in Salvador that provided systematic care to poor AIDS patients who had 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."

At the state's AIDS ward, Dr. Nanci lamented, "We are still full of wasting patients. The difference now is that they come from the interior, where no new services have been created. Access to therapies has been democratized, but health has not." Many doctors do not put drug addicts and the homeless on antiretroviral therapy. They say that there is no guarantee that these people will continue the treatment and that they are concerned about the creation of viral resistance to ARVs. Thus, against an expanding discourse of human rights and pharmaceutical possibilities, we are here confronted with the on-the-ground limits of infrastructures wherein a new life with AIDS can be realized, but only in a limited way.

We can understand the conflicting effects of late liberal governance only 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—and grassroots work must address the social determinants of patients' conditions or make those markers invisible. From the perspective of an outsourcing state, grassroots entities such as Caasah are important, if transient, social instruments of remediation. Yet, for AIDS patients, they become proxy families and communities, providing the context necessary to make ARVs work. Here medical commodities are used in tandem with other ways of claiming citizenship, and desperate and creative interactions occasion novel public sites in which rights and health are privatized alongside the emergence of novel political subjectivities.

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, Luis and Rose. Their added life was 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, she stated "is relative to each person. It requires a lot of will." Yet, far from representing a

natural vitality, this *will to live* has to be fabricated and asserted in the marketplace and in local medical worlds by those with the means, as limited as these are, to do so. Political subjectivity is here articulated through pastoral means, disciplinary practices of self-care, and monitored pharmaceutical treatment.

The politically ambiguous AIDS survivors with whom I worked had all engineered fragile islands of hospitality in which they could inhabit their unexpected lives. To have someone to live for and to be desired by was also a constant thread in their accounts. They all had a place they called home, some form of labor, a small, steady income, and a social network of sorts. In a pinch, they could still resort to Caasah. This institutional tie, as tenuous as it now was, remained vital to them. These AIDS citizens are active in the pursuit of health, although few are activists.

I also met Luis during that August 2005 visit. He was still working at Caasah. He was in charge of the institution's fund-raising activities. "I am not concerned with HIV. If there is medication, let's take life forward." In the preceding year, Luis had experienced kidney failure and had been hospitalized for two weeks. "Work keeps my mind occupied, and one needs projects and objectives to meet—if not, life has no meaning." "Becoming a father," he said, "is the best thing that ever happened to me." Davi, his adopted son, was now a happy seven-year-old. "He is my passion. He makes it all worthwhile."

Rose was doing great, as were her children. I was particularly happy to learn that her daughter had turned HIV-negative. Ricardo, her fifteen-year-old son, was helping two workers to finish the house's second floor. "It is my skyscraper. Water was infiltrating, and in the long run, I plan to rent it out." Rose intelligently navigates the local circuits of AIDS care. She had garnered the support of several NGOs, opened up a little business called Rose Tem de Tudo (Rose Has It All), and also devised a way of raising funds among religious philanthropists. She was proud of having been able to enroll her son in the project Teenage Citizen, which dona Conceição was running with World Bank funds.

Later that week, I met with dona Conceição. She was proud of her new project, which employed 120 children of AIDS patients in local industries, but she also regretted that hers remained the only institution to address AIDS in the streets. Her funds from a World Bank project would last only a year, and she still cared for some two hundred homeless families living with HIV/AIDS. "We cannot meet all the demand for help. It's a disgrace."

Without a doubt, Brazil has experienced a striking decrease in AIDS mortality. Seen from the perspective of the urban poor, however, the AIDS

treatment policy is not necessarily an inclusive form of care: Local AIDS triage services and social and economic rights for the poorest are sporadic at best. Brazil, which has innovated in making access to treatment a human right, must more fully define and implement a right to health that transcends medicines and individual demands and must ensure that primary health care and prevention are sufficiently robust to reduce vulnerability to disease (Biehl et al. 2009). Also at issue is a reconsideration of the systemic relations among pharmaceutical research, commercial interest, and public health care. We should think about more sustainable solutions to the obstacles posed by patentability and business control over medical science and care on the ground. Part of the solution may lie in comprehensive information and technology sharing among Southern countries—a paradigm that would enable poorer countries to develop health technology assessment programs, pool their manufacturing know-how, and unite in the fight for fair pricing.

Caasah's former residents are the new people of AIDS. They have by all standards exceeded their destinies. Now receiving treatment, Luis, Rose, and many others refuse the condition of leftovers. And they face the daily challenge of translating medical investments into social capital and wage-earning potential. Thus, from their perspective, health in a time of global health is a painstaking work-in-progress by monadic patient-citizen-consumers in relation to therapeutic markets, ailing public health infrastructures, and improvised medical collectives. They live in between-moments, between-spaces, scavenging for resources. At every turn, they must consider the next step to be taken to guarantee life. Theirs is the force of immanence. From these people, as poet João Cabral de Melo Neto (2005:82) puts it, "you can learn that the human being is always the best measure, and that the measure of the human is not death, but life."

Acknowledgments

I am deeply grateful to Adriana Petryna, Tom Vogl, Sebastian Ramirez, Adriana Petryna, Joseph Amon, Amy Moran-Thomas, Alex Gertner, Ari Samsky, Peter Locke, Ramah McKay, Mariana Socal, Raphael Frankfurter, Edward Fischer, and Peter Benson for their comments and help. Research and writing have been supported by Princeton University's Health Grand Challenges Initiative and the Woodrow Wilson School of Public and International Affairs.

Notes

1. See <http://www.unaids.org/en/Regionscountries/Regions/LatinAmerica/>, accessed April 29, 2012.

JOÃO BIEHL

2. See <http://www.who.int/hiv/topics/treatment/en/index.html>, accessed April 29, 2012.

3. See http://www.usaid.gov/our_work/global_health/aids/News/aidsfaq.html, accessed April 29, 2012.

4. See http://www.hbs.edu/rhc/global_health.html, accessed April 29, 2012.