

## 5 When people come first: beyond technical and theoretical quick-fixes in global health

*João Biehl*

### “It is the financial part of life that tortures me”

I begin with a poem by João Cabral de Melo Neto (2005) on the people of Northeastern Brazil, one of the poorest regions in Latin America. João Cabral writes of people who are one with that inhospitable environment, yet with a unique fluidity that creates potential. The poet grew up there, and it is there that I will take you in this chapter:

And from this indigent river,  
this blood-mud that meanders  
with its almost static march  
through sclerosis and cement  
and from the people who stagnate  
in the river’s mucus,  
entire lives rotting  
one by one to death,  
you can learn that the human being  
is always the best measure,  
and that the measure of the human  
is not death but life.

Life is in transit. This was certainly true for Evangivaldo. “What a joy you give me by coming back,” the 38 year-old man beamed as he saw me and photographer Torben Eskerod in December 2001 at Caasah, a community-run AIDS hospice in Salvador. Considered by many “the African heart of Brazil,” Salvador is the capital of the state of Bahia. It has an estimated population of 2.5 million, with more than 40 percent of families – like Evangivaldo’s – living below the poverty line. I could barely recognize him. But the stark visual side effects of AIDS therapies were the least of Evangivaldo’s concerns. “Today I woke up anguished. We have no gas to cook with.”

We were happy to help him out and told Evangivaldo that we had been trying to reach him for three days but had the wrong address. “I already had to move four times. The neighbors discovered that we have AIDS,” he said. “When it was just Fátima and me we could improvise things, but now that we have a child it is another

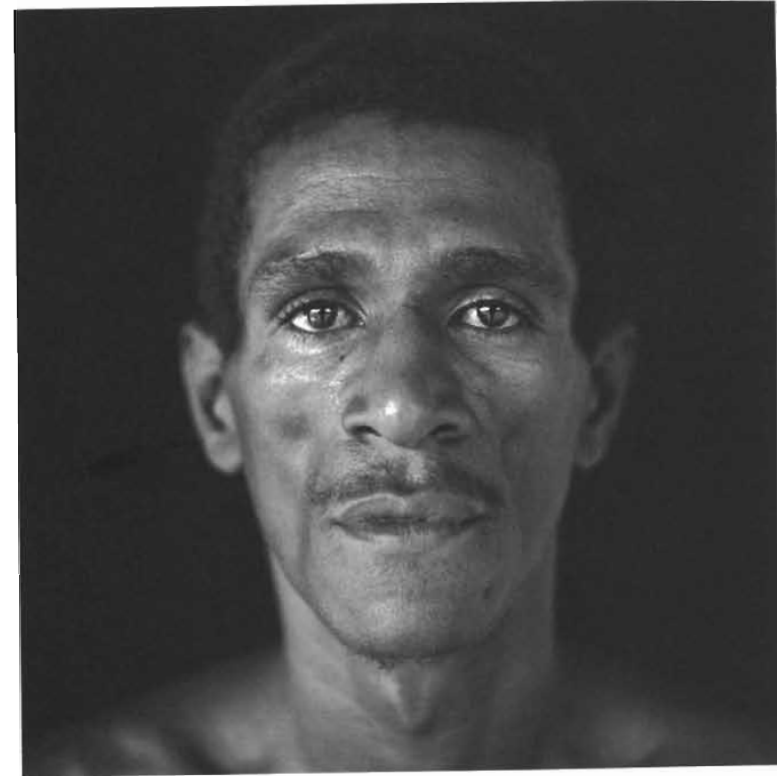


Image 5.1 Evangivaldo, 2001

matter. We can go hungry but Juliana cannot. I always take my ARVs [antiretroviral drugs], even if I just have coffee in my stomach.” Evangivaldo explained that “we did not plan to have a child. The condom broke. But now that she is here, I see that this is what I wanted most in life. I thought I would die. . .but now I have a fruit of the earth.” He paused and then added: “*It is the financial part of life that tortures me.*”

Via pharmaceuticals and at the mercy of a volatile economy, Evangivaldo and his loved ones lived in flux. Like millions of other poor AIDS patients worldwide who now have access to treatment, he struggled to move out of the stream of history and into a technologically prolonged life. Scavenging for resources and care, Evangivaldo conveyed desperate and extraordinary efforts to swerve and exceed constraints of all kinds. As he drove to singularize out of economic death, he also expressed world-altering desires. This chapter is about Evangivaldo and the social fields that the new people of AIDS invent and live by. Their drives and doings upset

probabilities, bias estimates, and expand the limits of what can be known and acted on in the new world/market of global health.

**Model policy**

Brazil accounts for 43 percent of all HIV/AIDS cases in Latin America. An estimated 730,000 Brazilians were living with HIV/AIDS in 2007 – an adult prevalence of 0.6 percent (Figures 5.1, 5.2). For about a decade, incidence has hovered between 20 and 25 per 100,000 for men and between 10 and 15 per 100,000 for women. 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 socio-economic 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 anti-retroviral therapy (ART) (Figure 5.3). This policy resulted from potent rights-based social mobilization 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 healthcare system – AIDS activists were the first group to effectively equate this right to drug access. Some 200,000 Brazilians currently take antiretroviral drugs paid for by the government. The government managed to reduce treatment costs by promoting the production of generics. It also negotiated substantial price reductions from pharmaceutical firms.

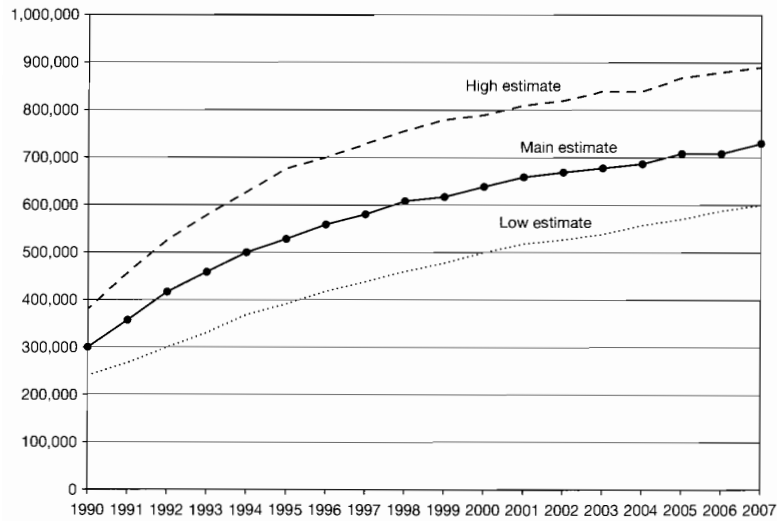


Figure 5.1 Number of people living with HIV, Brazil

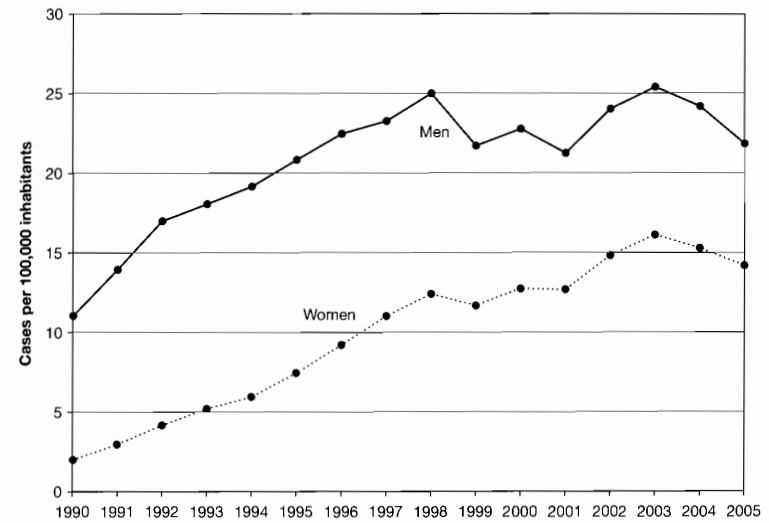


Figure 5.2 AIDS incidence, Brazil

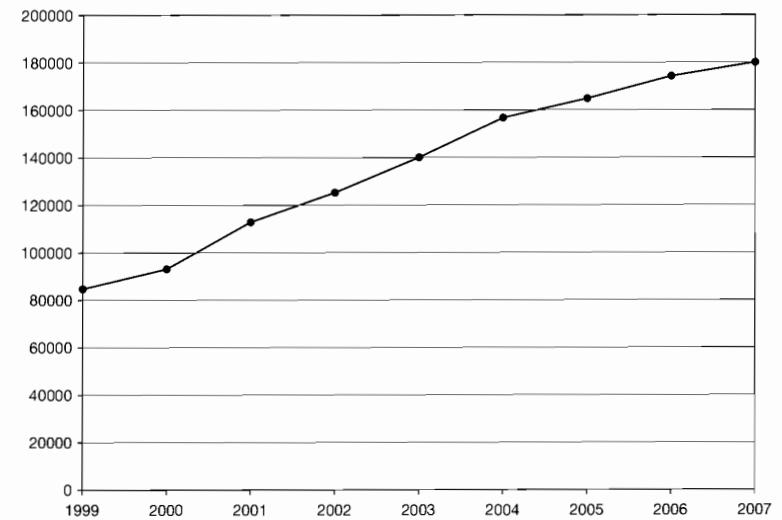


Figure 5.3 Number of patients on ART, Brazil

According to the Health Ministry both AIDS mortality and the use of AIDS-related hospital services fell by more than 50 percent (Figure 5.4). Perhaps even more impressive is the decline in mortality during the first year after diagnosis (Figure 5.5), signifying the transformation of HIV/AIDS from an acute to a chronic disease. Brazil's bold, multi-actor, and large-scale therapeutic response to AIDS has made history (Figure 5.6). It empirically challenged the economic and medical orthodoxies that treating AIDS in resource-poor settings was infeasible and that poor patients could not adhere to these 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 was spreading most rapidly. How would people such as Evangivaldo and Fátima transform a death sentence into a chronic disease? What social innovation could make such medical transformation possible?

**Moving in the direction of the incomplete**

For over ten years, I have explored the impact of the AIDS treatment rollout throughout the country's government, health systems, and personal lives. I 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 ARVs, I wanted to open a window into the real-life outcomes of novel national, international, and corporate policies (Biehl

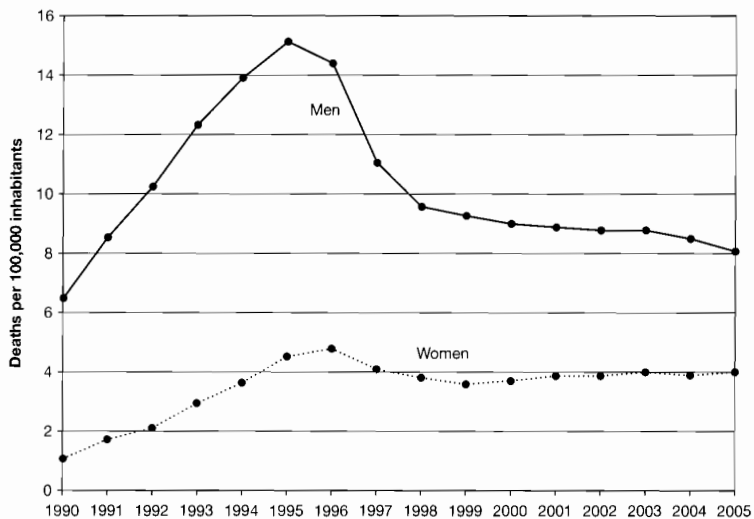


Figure 5.4 AIDS mortality rate, Brazil

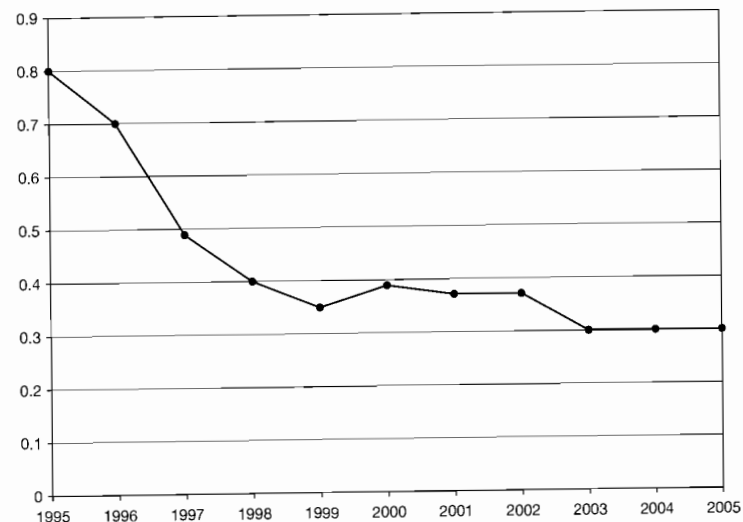


Figure 5.5 AIDS mortality in first year after diagnosis, Brazil

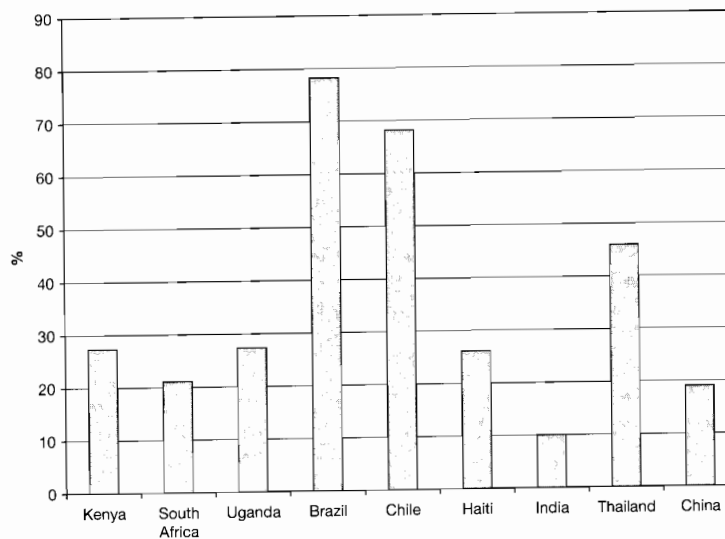


Figure 5.6 ART coverage among people with advanced HIV, 2006

2007). Broadly speaking, I have been concerned with the arts of government that accompany economic globalization and the remaking of people as market segments (specifically, therapeutic markets). How do citizen-consumers draw from government and make it resourceful as they negotiate the vagaries of the market and survival? When and under what conditions are marginalized people accounted for as population-subjects in new biomedical regimes?

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. Following the Brazilian lead, initiatives are being launched today, seeking to address AIDS therapeutically in places where treatments have been scarcely available. Whereas in the past, the field of international public health was dominated by multilateral and bilateral organizations, a complex matrix of partnerships (nongovernmental, philanthropic, industrial and governmental) has arisen and is shaping health interventions worldwide under the frame of security and humanitarianism (Fidler 2008) – 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 Gates Foundation, to corporate drug donation programs, to PEPFAR (the U.S. President's Emergency Plan for AIDS Relief), to exemplary pilot projects such as those of Partners In Health in Haiti and Rwanda, these various actors have elastic relationships with each other. They 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 (Reich 2002). Whatever differences there are across corporate, activist, and public health agendas, the new rubric of "value" appears to reconcile these differences and folds them into an ethos of collective responsibility. Arguably, participants can become impervious to critique as they point to dire global health statistics and their non-optional duty to act (i.e. to partner, making treatment accessible and saving lives – see Sachs 2005; Singer 2009).

So far, few, if any, institutions are in place to monitor this burgeoning and somewhat disordered "public goods" field (Biehl 2008; Samsky 2009). 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 are increasingly dominated by scientifically based measures of evaluation, revolving around natural experiments, randomized controlled trials, statistical significance, and cost-effectiveness (Duflo *et al.* 2008; Todd and Wolpin 2006) – a technical rhetoric aligned with the demand of funding organizations for technical solutions. Traditional public health initiatives are now slated in the category of "non-science" and this "scientific preoccupation" tends to overlook the on-the-ground dynamics of programs, assuming that they will work in other settings, replete with distinct institutions, practices and rationalities (Adams *et al.* 2008).

Indeed, much is side-stepped and remains unaccounted in this global form of experimentality and "post-politics" (Petryna 2009; Ecks 2005). How can donors be held accountable in the long-run, especially in this financially volatile time?

How do global health trends affect the role of governments and their human rights obligations? Moreover, how are other deadly diseases of poverty that have less political backing being dealt with? Which projections and value systems underscore policy-decisions and medical triage? Problems and questions that were not necessarily known in advance and that now have to be addressed as life-saving imperatives have been converted into pharmaceutical and new geopolitical capital.

In his recent book *Cold War, Deadly Fevers*, historian Marcos Cueto (2007) documents the story behind the Malaria Eradication Program that played a crucial role in Mexico's public health policy during the politically charged years of the Cold War era. While constantly keeping in view the campaign's international political implications, Cueto's detailed account of the way the eradication campaign unfolded on the ground leads him to unexpected anthropological terrains: he documents a profound disconnection between how the campaign was designed to work by the Rockefeller Foundation and elite national health experts, and the complex ways it was actually received by the indigenous residents of rural Mexico. In rural communities, many families simply refused to let the DDT sprayers into their homes, and there were cases when spontaneous protest even bordered on the edge of armed violence. After the first several years, even people who had complied with earlier rounds of DDT spraying angrily noted that it worked less effectively every time, and that many insects already seemed to be developing resistance and growing bigger instead of dying off.

It was in this charged historical moment that medical anthropology emerged as an applied science. Anthropologist Isabel Kelly, a former Berkeley student of George Foster, began collaborating with Héctor García Manzanedo and the Mexican Health Secretariat on rural projects in 1953. As the pair began researching how the malaria eradication program was being received in indigenous communities, they conceived their roles to be those of listeners and cultural brokers. Their report suggested many complex reasons why the program was not achieving its anticipated success, which stretched far beyond the already underestimated language barriers. For example, the medical anthropologists' report explored complex rotational housing patterns according to the seasons, meaning that families often seasonally abandoned the house that had been sprayed or preferred to simply sleep outside in the heat of summer. More fundamentally, indigenous communities often had their own healing systems and understandings of fever that coexisted uneasily with the public health information about malaria that the government distributed. And as the medical anthropologists ultimately pointed out, this environment of suspicion was underpinned by a fundamental difference in health priorities. In many communities, malaria was not conceived of as a major health problem or even a single disease, and many people in rural areas wondered why it was being addressed when their other more pressing health concerns were being ignored.

Cueto's complex portrait captures the fact that this collision between local values and international public health agendas was hardly just a fluke or footnote in the history of Malaria Eradication – it was a key reason why the campaign ultimately failed. Without paying attention to how this intervention became embedded in local

economies and politics, national health officials often treated social resistance as a communications problem in a population that needed to be educated, instead of reflecting on the structure of the intervention itself. The implications of these realities run deep for our health policies today. In 2007, the Gates Foundation revived the failed campaign, pledging to eradicate malaria from the world. A year earlier, the World Health Organization once again approved the spraying of houses as an appropriate part of malaria eradication. As Cueto notes, pyrethroid-soaked bednets and pharmaceuticals have become the technical fixes of a supposedly “new era,” the goal of malaria eradication now resurrected four decades after its original failure was declared in 1969 (see Bleakley 2009).

The fact is that magic-bullet approaches are increasingly the norm in global health – that is, the delivery of health technologies (usually new drugs or devices) that target one specific disease regardless of myriad societal, political and economic factors that influence health. Drawing from my study of the Brazilian therapeutic response to AIDS, this chapter explores the limits of the vertical-technical-fix approach in global health and the feasibility of “people-centered” initiatives. We need analytic frameworks and institutional capacities that move beyond the repetition of history and that focus on people: on-the-ground involvements that address the politics of both control *and* non-intervention, the fragmentation of efforts, the presence of heterogeneity, the personal and the interpersonal, people’s inventiveness.

It is time to attribute to the people we study and describe the kinds of complexities we acknowledge in ourselves, and to bring these complexities into the picture of global health. Policy and popular accounts tend to cast people as helpless victims, over-determined by environment, history, and power, or as miraculous survivors who bear witness to the success of external aid. Details are suspended. Broken institutions, rifts that deepen, and larger political economies in which these lives unravel seem peripheral to both analysis and activism. In the social sciences, methods such as randomized trials have been hailed as magic bullets in the quest for scientific evidence and for keys to unlocking the mysteries of health and development. People are put into pre-conceived molds. The human populations that constitute the subjects of health and development studies are not just the source of problems. Their practical knowledge may well yield effective solutions – experiential knowledge all too readily disqualified by sponsors of technical fixes in the search for quick results.

People’s everyday struggles and interpersonal dynamics exceed short-term experimental approaches and demand listening and long-term engagement (Biehl 2005; Scheper-Hughes 2008; Tsing 2004; Whitmarsh 2008). Anthropology’s task in the field of global health is to produce different kinds of evidence, approaching bold challenges such as the pharmaceuticalization of health care delivery and crucial questions such as what happens to citizenship when politics is reduced to survival – with a deep and dynamic sense of local worlds (Petryna *et al.* 2006). The anthropologist demarcates uncharted territories and tracks people moving through them. In the field, the unexpected happens everyday and new causalities come into play. An openness to the surprising and the deployment of categories that are important in human experience can make our science more realistic and hopefully better.

### “My politics is to see things humanly”

I first met Evangivaldo in 1997. Homeless and with contagious scabies, Evangivaldo had been sent from the AIDS ward of the state hospital to Caasah – one of the 500 Brazilian “houses of support” (*casas de apoio*) that helped poor AIDS patients navigate the precarious health system. Antiretrovirals were becoming available, but public institutions were barely functioning, and the government was increasingly outsourcing care to grassroots services. “I need to talk, to speak all truths,” I remember Evangivaldo saying through the door of a room that quarantined him: “I have this sad psychosis in my head.”

Evangivaldo’s parents died when he was young, and he was raised by an uncle. As a teenager, he moved to Salvador in the early 1980s: “I carried many sacks of flour on my back to buy my first pair of sandals, he said.

“Later, I escorted prostitutes to the ships that docked here.” He was struggling to belong: “There are people here who think that they are superior because of

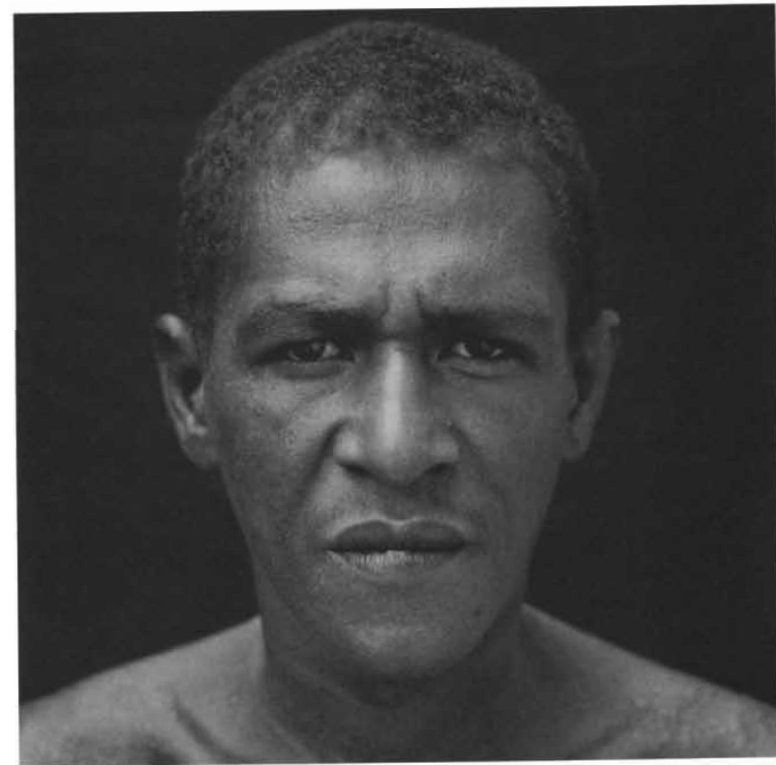


Image 5.2 Evangivaldo, 1997

the color of their skin, or because they have a doctor who likes them, or because they are in better health.”

Caasah was founded in 1992, when a group of homeless AIDS patients squatted in an abandoned hospital formerly run by the Red Cross. Soon, Caasah became a nongovernmental 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 underwent 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, and they fight for their lives.”

Evangivaldo was one of the few who got that chance. 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. “Did you ever see an AIDS patient in here hoping for the other’s well-being?” Evangivaldo asked me. In fact, residents were constantly pointing out each other’s faults and comparing clinical conditions. The other’s misbehavior or sickness was a measure of their own health progress. Money was also at stake. Caasah was facilitating application for AIDS disability pensions, and priority was given to those residents who showed change. People kept to



Image 5.3 Caasah in the mid-1990s



Image 5.4 Caasah in the mid-1990s

themselves. As one patient told me: “One Luis has died and another has emerged. I got used to the medication. Medication is me now. Today people only die from AIDS if they want to.” But Evangivaldo thought differently: “*My politics is to see things humanly*. The one who is strong now must help the weaker.” After a year in Caasah, Fátima came into his life, he said. “As I got better I told her ‘Like you, I have no family. I have nobody for me. Let’s live together.’ And she said ‘yes.’”

### In the meantime and what is outside biopower

There is no short cut to understanding how a technologically-prolonged life is achieved – be it 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 10 million people are in need of antiretroviral therapy. The battle for access has been hard-fought, and nearly 4 million are now on treatment in low and middle-income countries.

Global AIDS treatment rollouts rightly open the door to drug access, but they also exemplify the inadequacies of a magic bullet approach to health care. Drugs are ancillary to the full treatment of the disease. Alone, neither money nor drugs nor sophisticated pilot projects guarantee success. Healing, after all, is a multifaceted concept, and “healing” is no more synonymous with “treatment” than “treatment” is with “drugs.” Statistical strategies and profit motives hover above,

by and large missing the interpersonal networks that link patients, doctors, and governments, which are especially important in resource-poor settings, where clinical infrastructures are not improving. AIDS death and HIV infection keeps growing among the destitute. An estimated 3 million people become newly infected each year. For them, HIV/AIDS is one tragedy among many others.

These realities are not reducible to the theories we bring to the field. Numerous anthropologists have been using Michel Foucault's formulation of biopower – how natural life has been taken as an object of modern politics (1990; 2007) – to assess emerging assemblages of technology, medicine, and governance, particularly in the face of HIV/AIDS (Nguyen 2005; Comaroff 2007; Fassin 2007; Robins 2006). Yet this influential biopolitical analytic – “making live and letting die” – deserves deeper probing as it might assume transcendent forms of power and homogeneous people and overly normalized populations (Foucault 1990, 2007). As Ian Hacking acknowledged in his essay on how new kinds of people can be “made up” by medical diagnostics: “my concern is philosophical and abstract. . .and [I] reflect too little on the ordinary dynamics of human interaction” (1999: 162).

What is outside biopower? Traversing worlds of risk and scarcity, constrained without being totally over-determined, 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 non-state actors). Scholars and policy-makers are challenged to respect and to render publicly intelligible, without reduction, the angst, uncertainty, the passion for the possible and the travails that people like Evangivaldo, amid lifesaving interventions, are left to resolve by themselves and, too often, at the expense of others.

For over ten years, I have chronicled life in and out of Caasah. 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.

Evangivaldo, Torben, and I sat under a tree in the backyard, and we looked at the portraits Torben had made of the Caasah residents in 1997. With a simple chair and a black cloth against a brick wall, we had improvised a photo studio. Torben photographed each person and I recorded their life stories. “This work was important to me, it marked my history,” Evangivaldo said. Celeste, the director, joined us: “You really captured the person,” she told Torben, with a sigh. With a certain melancholy, Celeste admitted that “in the day-to-day work we really did not see this. . .we pretended that we knew who they were.”



Image 5.5 Luis and Torben, 1997

As for Evangivaldo: “I know that this is a kind of scientific work for people to see what we go through in Brazil, but I also want to show it to my doctor and the nurses. I want them to see how I changed.” Evangivaldo showed us the prescription for an anti-depressant that he also needed but couldn't purchase. “We already owe 75 reais at the pharmacy,” he said – that was half of his disability pension. “I wake up at 4:00 am and ride my bike for two hours to get downtown. I go door to door asking for a job. There are days when I cannot get the money we need and I panic. I hide in a corner and cry. Then I don't know where I am.” Yet, he found ways to transcend his sense of being choked. “I say ‘focus, Evangivaldo, focus, you will find your bike and your way home.’ And do you know why I manage to do this? Because my Juliana is waiting for me.”

With antiretroviral therapies available, healthy residents like Evangivaldo, Fátima, and Rose 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 a short-term recovery facility for patients sent by hospitals' AIDS wards and a shelter for orphans with HIV. Disturbingly, there was no systematic effort to track patients and their treatments once they left.

AIDS therapies are now embedded in landscapes of misery, and hundreds of grassroots services have helped to make AIDS a chronic disease also among the poorest in Brazil and beyond. This is not a top-down biopolitical form of control. The government is not using AIDS therapies and grassroots services as “techniques . . . to govern populations and manage individual bodies” (as anthropologist Vinh-Kim Nguyen has framed the politics of antiretroviral globalism – 2005: 126). As

I am arguing in the light of Caasah, the question of accountability has been displaced from government institutions, and poor AIDS populations take shape, if temporarily, through particular engagements with what is made pharmaceutically available. The political game here is one of self-identification. Proxy-communities, often temporary and fragile, and 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.

At the margins, both the institutional and pharmacological matters surrounding AIDS treatment undergo considerable flux. And poor AIDS survivors themselves live in a state of flux, simultaneously acknowledging and disguising their condition while they participate in *local economies of salvation* and articulate *public singularities*. Against the backdrop of a limited health care infrastructure and economic death and through multiple circuits of care, individual subjectivity is refigured as a *will to live*.

Philosopher Giorgio Agamben has also significantly informed contemporary biopolitical debates with his evocation of the *homo sacer* and the assertion that “life exposed to death” is the original element of western democracies (1998: 4). This “bare life” appears in Agamben as a kind of historical-ontological destiny – “something presupposed as nonrelational” and “desubjectified” (1999). A number of anthropologists have critiqued Agamben’s apocalyptic take on the contemporary human condition and the dehumanization that accompanies such melancholic, if poignant, way of thinking (Das and Poole 2004; Rabinow and Rose 2006). Whether in social abandonment, addiction, or homelessness, life that no longer has any value for society is hardly synonymous with a life that no longer has any value for the person living it (Biehl 2005; Bourgois and Schonberg 2009; Garcia 2008). Language and desire meaningfully continue even in circumstances of profound abjection (Biehl and Moran-Thomas 2009). Such difficult and multifaceted realities and the fundamentally ambiguous nature of people living them give anthropologists the opportunity to develop a human, not abstractly philosophical, critique of the non-exceptional machines of social death and (self) consumption in which people are caught. Against all odds, people keep searching for social recognition and for ways to endure, at times reworking and sublimating afflictions and constraints.

Acknowledging the insights and alternative human capacities that grow out of abjection also forces us to inquire into how they can be part and parcel of the much needed efforts to redirect care. The need for subjective texture thus also raises broader anthropological questions about ethnography’s unique potential to bring the private life of the mind into conversations about public health and politics. Rather than ethnographically illustrating the silhouettes of biopolitical theory, new ways of thinking about political belonging and subjectivity force us instead to reconsider this theoretical framework’s very terms (Rancière 2004; Fischer 2009).

Gilles Deleuze (2006), who did not share Foucault’s confidence in the determining force of power arrangements, is helpful here. According to Gilles Deleuze, desire, via the inventions, escapes, and sublimations it motivates, is constantly undoing – or at least opening up – forms of subjectivity and territorializations of

power. Even the concept of *assemblage*, taken up not long ago by Aihwa Ong and Stephen Collier to name emergent global configurations – like “technoscience, circuits of licit and illicit exchange, systems of administration or governance, and regimes of ethics or values” (Ong and Collier 2005: 4) – has desire, in Deleuze and Guattari’s definition in *Kafka: Toward a Minor Literature* (1986), at its core. For Deleuze and Guattari, assemblages are contingent and shifting interrelations among “segments” – institutions, powers, practices, desires – that constantly, simultaneously construct, entrench, and disaggregate their own constraints and oppressions (1986: 86). This emphasis on desire and the ways – humble, marginal, minor – that it cracks through apparently rigid social fields and serves as the engine of becoming figures centrally in Deleuze’s divergences from Foucault, whose archaeology of the subject traces the ways in which he or she is constituted and confined by the categories of expert discourses, for example, in what, again, might be crudely sketched as a vertical or top-down movement.

Epistemological breakthroughs do not belong only to experts and analysts. The cumulative experiences of “the unpredictability of the political and social effects of technological inventions” – borne by people navigating contemporary entanglements of power and knowledge – are also epistemological breaks that demand anthropological recognition (Canguilhem 1998: 318). Long-term engagement with people is indeed a vital antidote to what economist Albert Hirschman identifies as “compulsive and mindless theorizing.” The quick theoretical fix has taken its place in our culture alongside the quick technical fix. For Hirschman, as for the anthropologist, people come first. This respect for people, this attention to how policies are put together – how they take institutional hold and fit into unequal social relations – makes a great deal of difference in the kind of knowledge we produce. As Hirschman writes, “In all these matters I would suggest a little more reverence for life, a little less straitjacketing of the future, a little more allowance for the unexpected – and a little less wishful thinking” (1971: 338).

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 Evangelvaldo affirms. It is not enough to simply observe that complicated new configurations of global, political, technical, biological (etc.) segments exist or are the temporary norm. We must attend to the ways these configurations are constantly constructed, un-done and re-done 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.



### Persistent inequalities and the scientific aura of pretending not to know

By 2000, the Bahian health officials claimed that a plateau had been reached and that AIDS incidence was on decline, ostensibly in line with the latest statistics pointing to the success of the country's control policy. But the AIDS reality I saw in the streets of Salvador contradicted this profile, and a central concern of my ethnography has been to expose the limits of surveillance and to generate some form of visibility and accountability for the hidden AIDS epidemic experienced by the most vulnerable and marginalized.

While observing life literally in-the-making at Caasah, I also chronicled the work of Dona Conceição, a nurse, who provided meals and some form of care to one hundred homeless AIDS patients, involved in illicit economies and supporting their children. "Medical services never meet the demands, and civil society has abandoned them," Dona Conceição told me. "I try to alleviate things a bit. I am tied to them in spirit."

I met with officials at the state run epidemiological surveillance service and asked them to verify whether some of these street patients who reported being treated at the state's AIDS ward were registered in their database. These patients were nowhere to be found. Yet, from my vantage point, they were dying a very public death – a destiny that Evangivaldo other patient-citizens were trying to escape through extraordinary efforts.

Interestingly, Brazil's computerized registry of patients on antiretroviral therapy includes data on treatment combinations, dosages and CD4 counts, yet it does not include specific social indicators. Without knowing where these patients live, we



Image 5.6 Dona Conceição and her "street patients."

cannot assess the policy's national coverage; without knowing education or income levels, the class dynamics at work in treatment access remain unknown; without a sense of the social networks of this new medical population, we don't know about adherence patterns and how drug access translates into better health. The fact is that, on the ground, the AIDS treatment policy reproduces the fault lines of race and poverty and we see uneven outcomes for patients, as well continuous stigma and discrimination, even from health professionals. A recent survey on mortality in the state of São Paulo revealed that AIDS is two times more fatal among blacks than it is among whites.

These trends show the need for more in-depth program evaluations. Yet the field of global public health, AIDS notwithstanding, is dominated by econometric analysis with its powerful claims to statistical and epistemic superiority (Heckman and Vytlačil 2007) but skewed generalizability and short shelf-life. As economist Angus Deaton notes, a trial-based "randomization in the Tropics" is also unlikely to shed light on the keys to development because such endeavors do not offer insight into *why* specific programs do or do not work. Excluding observation and what deviates from ideal conditions, "the technical fixes fail and compromise our attempts to learn from the day" (2009:47). The all-too-human questions "why here, why me, why now?" – so crucial to anthropologists – are often elided.

To grasp how AIDS victims disappear from public accounting, I collaborated with local epidemiologists. We gathered the death certificates of all AIDS patients in the state's AIDS ward over six years. We found that over half died in their first hospitalization, suggesting that the majority of these people only gained access to hospital services at the point of death. We also discovered that only 26 percent of these AIDS cases were actually registered by the surveillance service. We were intrigued. What made some of these AIDS cases officially visible and the majority not? Compared to patients who died during their first hospitalization, patients who died during a later hospitalization were two thirds more likely to be registered. Moreover, men who self-identified as bisexual or homosexual were 50 percent less likely to be registered than those that reported heterosexuality.

These voids and biases were not just the result of precarious surveillance that could be addressed with a simple technical fix. The problem was rooted in three factors: first, the operating logic of a health care system that circumscribes service delivery to about 30 percent of the demand – those patients who autonomously search for continuous treatment, fighting for their place in the overcrowded and underfunded services; second, a powerful physician sovereignty that can neglect and deem some patients unworthy; and third, the problematic ways in which marginalized people living with HIV/AIDS respond to their disease given a fragmented system of care and the illicit economies they often engage. "They come in dying," the social worker told me. "They never heal. Without a home how can they adhere to treatment? There must be thousands like them." There are no records tracing these people's plights and the complex social and economic interactions that exacerbate infections and immune depressions remain unaccounted for.

My colleagues and I wrote a report to the Bahian Health Secretariat informing them of the existence of this hidden AIDS epidemic. I learned later that this report

was shelved. Within these local force fields, the country's innovative AIDS treatment policy was coming alive and gaining international attention, islands of care and a triage-like state took form, and social death continued its course.

### **From collective epidemic to a highly privatized politics of survival**

When I returned to Salvador in 2001, I worked with the roughly thirty homeless patients still under the care of Dona Conceição. They were now 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 then, as Carisvaldo put it, "We push life forward anyway." Several said that they had begun picking up free antiretrovirals at the hospitals, but that they had stopped using them. According to Roberto, "Medication alone will not solve anything." His friend Luis 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.

What I witnessed there speaks volumes to the tragic unfolding of the AIDS epidemic among the marginalized. One morning, two girls aged thirteen and fifteen, had joined the "street tribe." They had just escaped forced prostitution. Two of the homeless AIDS patients found them wandering and brought them to the soccer stadium, where they forced them again, into sex. "I want to go home," one girl told me, shivering. As I was talking to them, child welfare officers showed up and said that they would take the girls back to their hometown. As the police van was leaving, the street cleaners who had been there all along turned to the remaining people, and mockingly said: "Your fresh flesh is gone."



*Image 5.7 Homeless*

At the end of that week, I went to Brasília, the country's capital, 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. Cardoso promoted the AIDS policy as evidence of the supposed success of his reform agenda – a state open to civil society, activist vis-à-vis the market, and fostering partnerships for the delivery of technology. "All the NGO work, treatment legislation, struggles over drug pricing are new forms of governmentality in action. . . engineering something else, producing a new world."

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." Or, in the words of economist and former health minister José Serra, "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. These public actions are seen as "wider and more efficacious than state action" (Cardoso's words). In practice, activism has enhanced the administrative capacity of the reforming state.

In my interview with Dr. Teixeira I mentioned the AIDS reality I had just observed in the streets of Salvador. "It is a portrait of Brazil," he said. "I am not happy with the work being done with AIDS and poor populations. We have to identify a working strategy." Dr. Teixeira made clear the state's position of basically deferring care to community organizations and added: "To work with these people is not the same as working with the elite in São Paulo, but effectiveness is also possible. If I get 20 to 30 percent of effectiveness with these people this is already a very important step." As I heard him, I was reminded of the 26 percent rate of AIDS registration in the Bahian surveillance service, of the ways in which the local state circumscribes populations for service. "We have to improve this," repeated Dr. Teixeira.

But the AIDS NGOs that were supposed to have taken over assistance "have long lost idealism and passion," activist Gerson Winkler bitterly told me. Winkler has lived with HIV/AIDS for over two decades and is one of the policy's most vocal critics: "Now it's all a game of make-believe," he said: "I select a clientele and pretend that I do a project, you pretend that you see it, the government pretends that it is monitoring it, and we all pretend that the results are true. It is a farce to think that NGOs can be the executor of state services." Asked about this criticism, Dr. Teixeira responded: "Did bad things happen in the process? Yes, but without outsourcing care there would not have been advancements either. Evolution is never unidirectional – it is forward and backward. We hope that it is two steps forward and one backward."

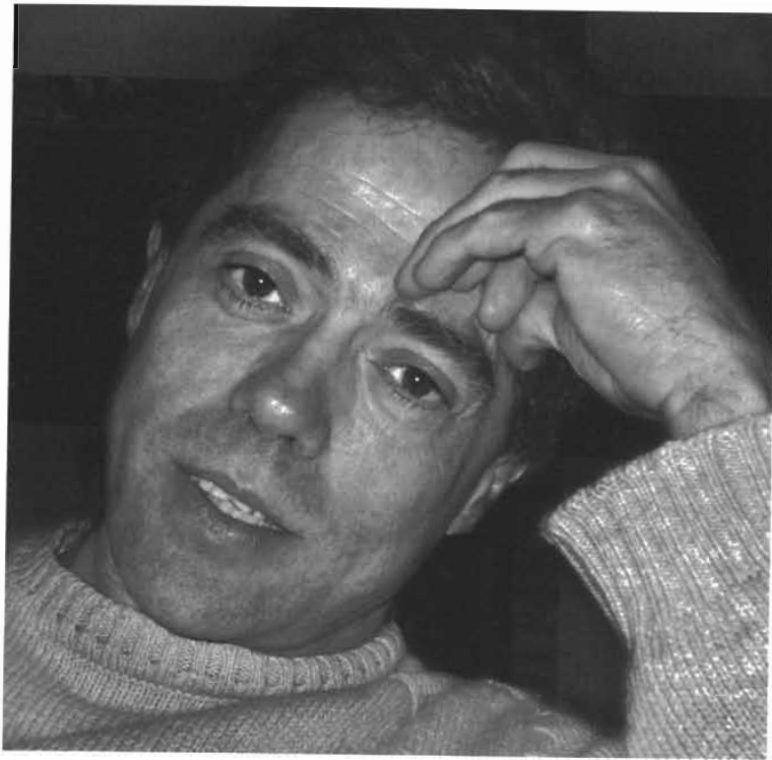


Image 5.8 Gerson, 2005

Winkler lamented that in this dance, AIDS politics had become increasingly atomized and that poor patients had been reduced to scavenging for assistance. “Stigma is constant,” he continued. “Most poor patients have never been formally employed. It is very difficult to help them develop a work mentality and place them in the market.” In other words, in the story I am telling you, we see 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 highly privatized politics of survival.

Evangivaldo’s trajectory, like those of many others, shows how empowering pharmaceutical access can be, but also how much additional effort is required to transform drugs that are “accessible” into drugs that are effective in the everyday lives of poverty-stricken patients. A vertical, top-down mass campaign against a disease, while valuable, leaves unaddressed the social realities that co-construct health outcomes (Easterly 2006, 2008). Health policies need to be directed at *people*, not simply disease.

The most prominent proponent of an approach that innovatively blends the vertical technological intervention with a horizontal focus on making health systems work is an anthropologist himself, Dr. Paul Farmer (2001, 2003). He and his colleagues at Partners in Health work with local communities in Haiti, Boston, Peru, and now Rwanda. Local clinics become a nexus of care, integrating HIV/AIDS treatment and prevention activities, while also attempting to address co-infections and the new medical problems that 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. In rural Rwanda, for example, each patient receiving antiretroviral drugs also receives food for five people. Although this *biosocial* model may be rejected by public health orthodoxies on the basis that it is not “cost-effective” or “sustainable,” it nonetheless expands the realms of feasibility and helps to shape new standards of care and intervention (Farmer 2008).

Real life has to be put back into the purview of AIDS policies. This requires going to where people are. Pauper patients, with no political voice, have been disregarded not due to the government’s inability or ignorance necessarily. Where there has been an active HIV search, testing and care – in Brazilian maternity wards, for example – infection has been curtailed. Why not, then, reach out to other vulnerable groups and discuss interventions *with* them? We need to innovate and find ways to make testing, treatment and sustained assistance available to groups that escape categories yet suffer most from the epidemic.

### Addressing the entanglement of people-disease-policy and market dynamics

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, the goal of eradication is an elusive target (Brandt 1985; Cueto 2007). Just as medical know-how, international political dynamics, and social realities change, so are biological systems in flux – bugs get resistant, new infections appear. A more complex model of this flux of people-disease-policy *and* market dynamics is required – and this, calls for innovative partnerships and methods.

In summer 2008, Amy Moran-Thomas shadowed health officials and medical NGO workers in northern Ghana as they worked on malaria prevention and deworming campaigns. And yet, during community visits she saw these efforts often went unheeded – treatments not taken, water filters for guinea worm and bed nets sitting in a corner, unused. Educational campaigns were trying to address this apparent negligence, but the problem ran deeper. When she asked parents what their primary health concerns were, they spoke of walking miles to find clean water

during the dry season and struggling with diabetes in an environment where so much cheap imported food was the only alternative to hunger (Moran-Thomas 2009). In other words, interventions seemed to ignore the complex preventative and environmental health issues most central in their lives.

Consider the widely-cited study by Michael Kremer and Edward Miguel on curing worm infections in rural Kenya. Miguel and Kremer 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 then observed a puzzling turn of events when they followed a group of families outside the original study after the trial had ended (2007). 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 to anemia and school truancy, then why were better-informed families not treating their children?

Again, we have a case in which the interpersonal relations and needs of people on the ground elude controlled studies, and the question of how to learn to bring



Image 5.9 Guinea worm ad and market in Northern Ghana

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’s success largely re-framed in terms of providing and counting the best medicines and newest technology delivered, what space remains for the development of low-tech or non-tech solutions (such as the provision of clean water) that could prove more sustainable and ultimately more humanistic?

Back in Brazil, with patients taking advantage of new antiretroviral drugs, the annual HIV/AIDS budget increased to \$562 million by 2006. In spite of the country’s generic production capacity, about 80 percent of the drugs dispensed are patented. “We are moving toward absolute drug monopoly,” Michel Lotrowska, an economist working for Doctors Without Borders in Rio de Janeiro, told me. “We have to find a new way to reduce prices; if not, doctors will soon have to tell patients ‘I can only give you first-line treatment, and if you become drug resistant you will die.’”

Recently, I asked a pharmaceutical executive how the private sector and the governments that his company was partnering with in Africa were thinking about this problem. For him, the crux of the matter was patient compliance. “If this is taken care of,” he said, “then second-line treatments will not even be necessary.” Moreover, he said “drug distribution systems should be improved to guarantee treatment consistency.” Last, he told me “We need to invest in basic science and have better drugs to begin with.” Patents and complex social and technical realities that might hinder best diagnostic practice or compliance do not enter into this global health conversation.

During recent research in Salvador, I learned that medical opinion-makers were urging doctors to prescribe T-20 as a first line treatment instead of using it as rescue drug. T-20 is a new drug that greatly helps patients with resistance to previous treatments at an annual cost of \$20,000 per patient. I also heard of cases where doctors began prescribing the rescue drug Kaletra at the time of its launch in the United States, before its registration in Brazil. These doctors referred patients to a local AIDS NGO and to public-interest lawyers who pressured the state to provide drugs not yet approved by the country’s FDA. In the face of pervasive pharmaceutical marketing enmeshed with social mobilization, regulatory incoherence thrives. Meanwhile, activist policy makers have to keep inventing strategies to keep the country’s AIDS treatment rollout in place.

India has been a pivotal country in the last decade, taking advantage of the transitional period instituted by the World Trade Organization to allow member countries to enshrine strong patent protections into law. During this period, India specialized in the generic manufacturing of patented HIV/AIDS drugs, which played an integral role in driving down prices and ensuring treatment access in resource-poor countries. But since 2005, generic manufacturing of patented drugs is now strongly prohibited. This could not come at a worse time as patented drugs like Tenofovir and Efavirenz have replaced preexisting first line treatments and become the widely accepted standard of care.

As a last resort, governments might issue “compulsory licenses” which would allow them to manufacture or import generics in a time of crisis without consulting the patent holder. Although the license usually guarantees the patent owner a royalty

fee of around 1 percent of generic sales, Thailand and Brazil still significantly lowered costs when they recently issued compulsory licenses for Efavirenz and imported an Indian generic. The drug is used by more by 75,000 Brazilians and activists praise this move as an important advance in the widening of access to the newest and most expensive therapies. But issuing compulsory licenses is not a long-term, sustainable solution. Due to recent restrictions on generic imports, the compulsory license requires countries to have internal pharmaceutical manufacturing capacity, meaning that most resource-poor countries cannot utilize this tiny flexibility built into the reigning intellectual property regime.

### The judicialization of the right to health

Across Brazil, patients are turning to courts to access prescribed drugs. The rights-based model of demand for access to AIDS therapies has “migrated” to other diseases and patient groups. Although Brazil has the developing world’s most advanced HIV/AIDS program, many of its citizens still go to local pharmacies only to find that essential medicines are out of stock. Brazil is also one of the fastest-growing pharmaceutical markets in the world. Doctors increasingly prescribe and patients demand new drugs, some with questionable benefit. Faced with high cost or no availability, many individuals are suing the government to obtain drugs (see Biehl *et al.* 2009).

Although lawsuits secure access for thousands of people, this *judicialization of the right to health* generates enormous administrative and fiscal burdens and has the potential to widen inequalities in healthcare. Six thousand and eight hundred



Image 5.10 Patient filing a treatment lawsuit with a public defense lawyer

medical-judicial claims reached the Solicitor General’s Office of the State of Rio Grande do Sul in 2006, for example, an increase from 1,126 in 2002. By 2008, an average of 1,200 new cases were reaching the Office per month. In 2008, US\$30.2 million was spent by this state of 11 million people on court-attained drugs. This expense represents 22 percent of the total amount spent on pharmaceutical drugs that year and 4 percent of the state’s annual projected health budget. About a third of current claims are for high-cost drugs not provided through the public health-care system. These claims surely account for a large proportion of state expenses.

Interestingly, a ruling by the Supreme Court in 2000 concerning an AIDS patient demanding access to a newer antiretroviral drug continues to inform the rulings of pharmaceutical provision in both state and federal courts. In his ruling, Minister Celso de Mello argued that the AIDS pharmaceutical assistance program was the actualization of the government’s constitutional duty to implement policies securing the population’s health. As the concrete embodiment of the need for “programmatically norms,” the AIDS program acquired an inherent judicial value in Mello’s ruling. As soon as the needy have medicines, according to Mello, the government’s legal responsibility for implementing programmatic norms that secure health are fulfilled and cease to be “an inconsequential constitutional promise.” In this rendering, the immediate assurance of the right to health through medicines circumvents questions about the limitations of policy, knowledge or resources.

Recent interviews reveal conflicting views. Many judges and public defenders working on the right-to-health cases feel they are responding to state failures to provide needed drugs, and some judges admit a lack of medical expertise to make informed decisions consistently. Administrators contend that the judiciary is overstepping its role, although some acknowledge that, because of these cases, distribution of several drugs has risen. Patient organizations have a highly contested role. Officials claim that at least some organizations are funded by drug companies eager to sell the government high-cost drugs. Patients encounter a bewildering and overburdened legal system in which injunctions granting access to life-saving drugs must be periodically renewed, typically resulting in interrupted treatment and medical complications.

The stakes are high and the debate is heated. What are the larger institutional and political implications of having the judiciary become the state executor? Are the courts a true alternative voice for those usually marginalized from the political process? Do we see a new form of “politicization” of the right to health that is making it more accessible, or an erosion of it, making it more privatized and more unequal?

### Fragile islands of hospitality

Finally this brings me back to Caasah. “If you look carefully, nothing has changed,” a tired Celeste told me during my last visit in June 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 they 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 on a limited way.

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 Evangivaldo. 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 they are, to do so. The AIDS survivors with whom I worked had all engineered fragile islands of hospitality in which they could inhabit their unexpected lives. They all had a place they called home, 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.

To have someone to live for and to be desired by was also a constant thread in their accounts. "Fátima had a stroke," Evangivaldo told me the last time I saw him:

She hurts inside because she cannot help. But I tell her that the important thing is that she is alive, that I do not mind being the man and the woman of the house. God knows everyone's gifts. The one who is strong now has to help the weaker. The important thing is to have a dignified life and to be healthy to see Juliana grow. That's what I have to say.

Without a doubt, Brazil has experienced a striking decrease in AIDS mortality. However, seen from the perspective of the urban poor, the AIDS treatment policy is not necessarily an inclusive form of care. Local AIDS services triage treatment, and social and economic rights for the poorest are sporadic at best. Brazil, which has innovated in access to treatment as a human right, must more fully define and implement a right to health that transcends medicines and individual demands, and ensure that primary health care and prevention are sufficiently robust to reduce vulnerability to disease. Likewise, at issue is a reconsideration of the systemic relation of pharmaceutical research, commercial interest, and public health care. We should think about a more sustainable solution 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 allow poorer countries to develop health technology assessment programs and to pool their manufacturing know-how and unite in the fight for fair pricing.

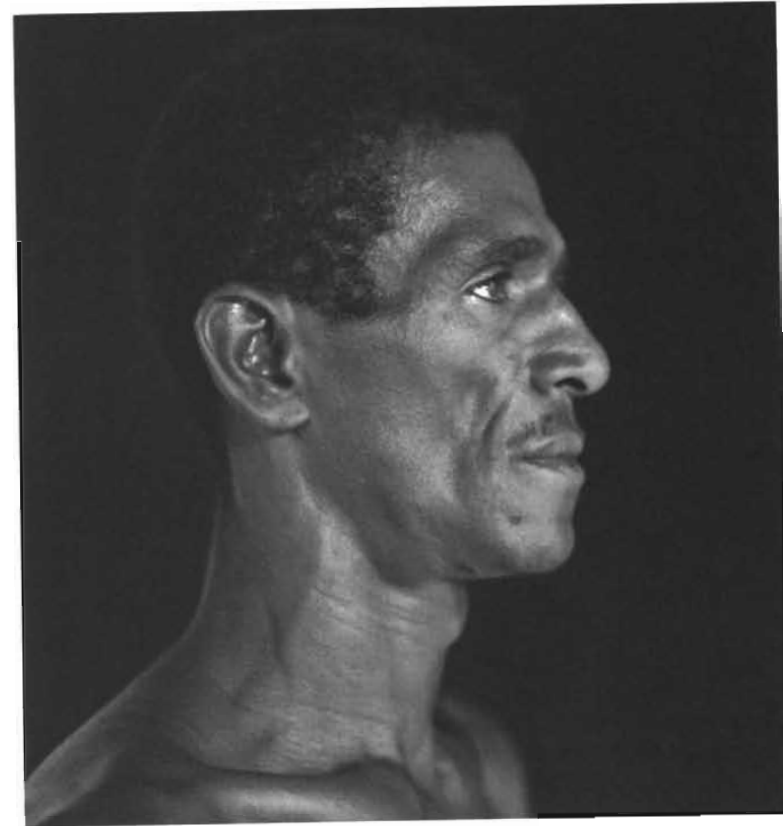


Image 5.11 Evangivaldo

Caasah's former residents are the new people of AIDS. They have by all standards exceeded their destinies. Now receiving treatment, Evangivaldo 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. They live 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, "you can learn that the human being is always the best measure, and that the measure of the human is not death but life."

Continually adjusting itself to the reality of contemporary lives and worlds, the anthropological venture has the potential of art: to invoke neglected human potentials and to expand the limits of understanding and imagination – a people yet to come. Thus at stake is also our formative power to generate a "we," an engaged audience and political community, that has not previously existed – our craft's potential to become a mobilizing force in this world.

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## Part II

# Capital's margins: the political ecology of the slum world