
Will to Live: AIDS Drugs and Local Economies of Salvation

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Photographs by *Torben Eskerod*

Brazil's groundbreaking response to AIDS combines prevention strategies with the distribution of free antiretroviral therapies (ARVs). This policy was initiated in 1996 through an inventive combination of activist forces, the interests of a reforming state, international institutions, and the pharmaceutical industry. Some 170,000 people are currently taking anti-HIV drugs that are paid for by the Brazilian government. Both AIDS mortality and the use of hospital services have subsequently fallen by more than 50 percent, and this policy is widely touted as a model for stemming the AIDS crisis in the developing world.

But how do individual sufferers fare in the long term as they engage with this large-scale intervention, particularly in poor urban areas, where the epidemic is spreading most rapidly?

In 1997 and in 2001, Torben Eskerod and I worked in Caasah, a community-run AIDS hospice in the city of Salvador, in the Brazilian state of Bahia. Caasah was founded in 1992 when a group of homeless AIDS patients, former prostitutes, transvestites, and drug users squatted in an abandoned hospital formerly run by the Red Cross. Soon, if surprisingly, Caasah became a nongovernmental organization and began to receive funding from a World Bank loan disbursed through

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the Brazilian government. Throughout the country, other “houses of support” (*casas de apoio*) like Caasah mediate the relationship between AIDS patients and the haphazard, limited public health care infrastructure. However, in order to belong to these makeshift institutions of care, people must break with their old habits, communities, and routines as they forge new biographies.

“Caasah had no government,” recalled Celeste Gomes, Caasah’s director: “They did whatever they wanted in here. Everybody had sex with everybody, they were using drugs. . . . There were fights with knives, broken bottles, the volunteers had to hide in the bathroom. Police officials came here all the time, threatening to kick us out, saying that there was no command here, that all these people were marginals.”

By the mid-1990s, the unruly patients in Caasah had been evicted, and a smaller version of the group began to undergo an intense process of resocialization mediated by psychologists and nurses. Patients who wanted to stay in the institution had to change their antisocial behaviors and adhere to medical treatments. Many adopted religion as an alternative value system. As Celeste put it, “With time, we domesticated them. They had no knowledge whatsoever, and we changed this doomed sense of ‘I will die.’ We showed them the importance of using medication. Now they have this conscience, and they fight for their lives.”

With a simple chair and a black cloth against a wall, we improvised a photography studio outside Caasah’s main building in March of 1997. Torben photographed each person as he or she wished to be portrayed, and I recorded their stories, past and present.

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

At the state hospital I learned of the existence of a triage system (for AIDS patients), which Caasah is part of. “Homeless AIDS patients remain outside the system,” one of the hospital’s social workers told me. “Doctors say that they do not put these patients on ARVs, for there is no guarantee that they will continue the treatment. They are concerned about the creation of viral resistance to medication.” The hospital’s leading infectious disease specialist confirmed that “in

theory, obviously, the doctor cannot condemn a drug user patient not to take medication . . . but the fact is that the homeless patient does not return for routine ambulatorial checkups. So what I do is to tell the patient that he has to come back. If he returns and demonstrates a strong will, we begin treatment. . . . But they never, or rarely, come back.”

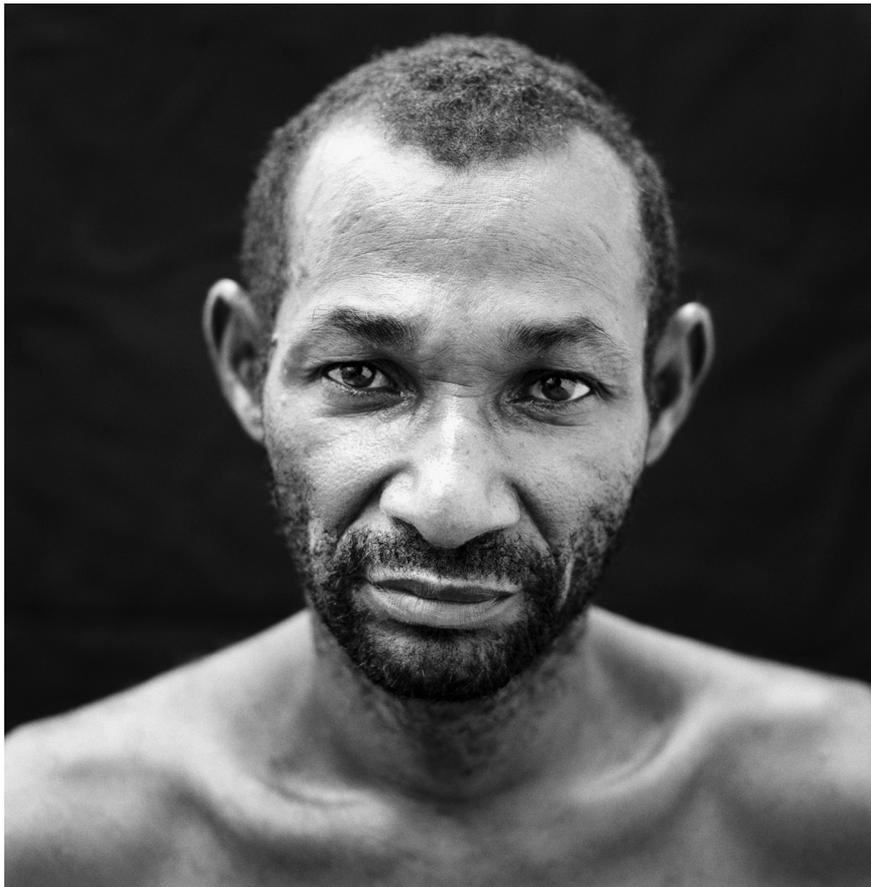
We looked for our former collaborators and tracked down those who had left Caasah. Some had died; others survived, married, and had children. As Torben took their portraits once again, they told us about all sorts of financial pressures, battles over discrimination, and the difficulty of obtaining access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

These AIDS survivors live in a state of flux, simultaneously acknowledging and disguising their condition while they participate in local economies of salvation. The political economy of AIDS, spanning both national and international institutions, creates an environment within which individuals and local AIDS organizations are codependent and simultaneously recraft positions and possibilities with every exchange. Their transactions are legitimated by a humanitarian and pharmaceutical discourse of life saving and civic empowerment. In adhering to a regimen of life-extending drugs and making new and productive lives for themselves, patients are—in this discourse—saved. However, merely guaranteeing existence in such dire contexts, amid the dismantling of institutions of care, involves a constant calculus that goes well beyond numbers of pills and the timing of their intake.

Even as they search for employment, patients work hard to remain eligible for whatever the state’s paternalistic politics have made available—renewal of disability benefits, free bus vouchers, and additional medication at local health posts, to name a few. Being adopted by a doctor and becoming a model patient (by complying to treatment in spite of a miserable situation) greatly facilitates this. And this material calculus becomes all the more important as patients form new families and resume a life considered normal, which was previously impossible to them.

The AIDS patients photographed by Torben intimately engage us with both their personal stories and the larger issues around AIDS treatment and social inequality: How do they both reflect one another and differ among themselves? What makes them visible or invisible in their neighborhoods? What is their place in a nation’s order and in new medical regimes? How do we relate large-scale institutions and forces to local history and personal trajectories? What is the staying power of these subjects’ interior force of life? What might their stories, standing alone and taken collectively, suggest through their concatenation?

Public Culture



Luis, 1997.
Photo: Torben Eskerod

“Medication Is Me Now”

Will to Live

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

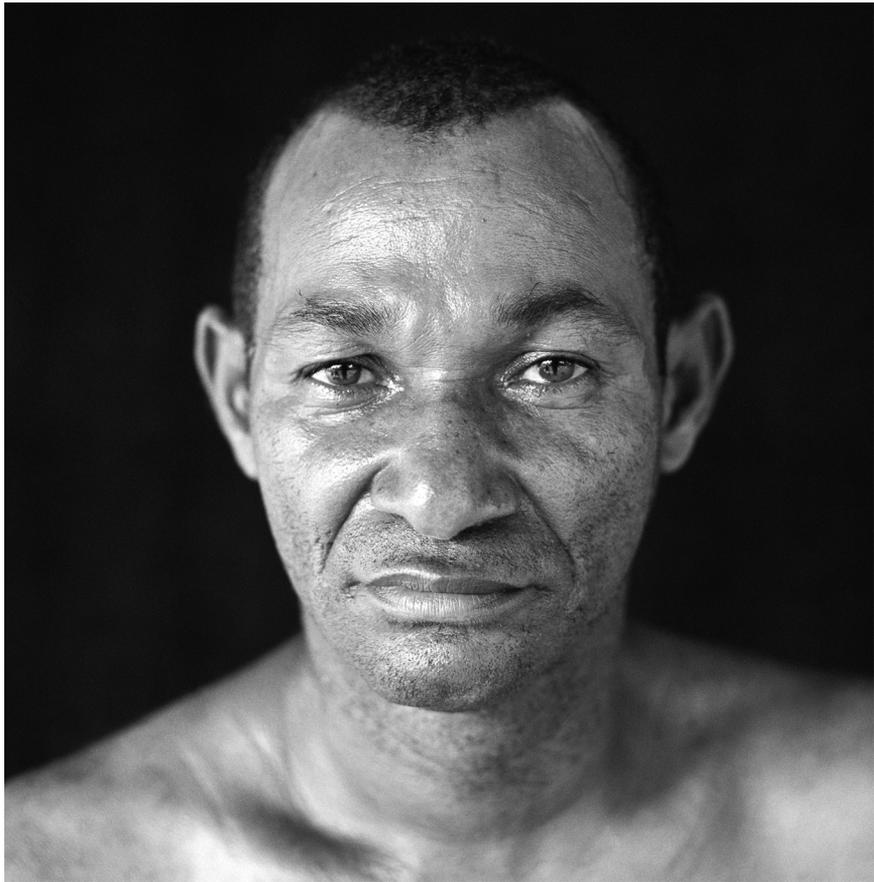
Luis was brought up by his mother, a *mãe de santo* in Candomblé (a priestess in a traditional African Brazilian religion): “At the age of nine my head was shaved, and I was also initiated as a child-saint.” Luis did not finish elementary school: “I had to work. I sewed clothing and later, I will not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

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

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

Luis loved to spread the word about his revival: “Soon I saw that one Luis had died and that another had emerged. Day after day, I feel better. If death wants me, it must search for me.”

Public Culture



Luis, 2001.
Photo: Torben Eskerod

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

For Celeste, “Luis is like a son.” He represents Caasah and the state of Bahia in national meetings of people living with HIV, and he runs HIV/AIDS prevention workshops in the interior. Even his doctor calls Luis “my teacher.” As Dr. Nanci told me, “I find this fantastic. . . . The patient had a history of self-abuse, remains poor, but rescues himself and teaches others to do the same. . . . Luis is strong and working.”

A disability pension and the salary he was earning as Caasah’s office assistant allowed Luis to rent a shack with a friend, to eat well, and to save a little, because, as he put it, “I want to have my own corner.” Luis insinuated he was dating. He also proudly told us that he had adopted an AIDS orphan in Caasah and was paying for the boy’s grandmother to take care of him.

I asked Luis whether religion had helped him adhere to a regimen of ARVs. “I think religion is within us,” he said. “I always believed in God, and now more than ever before. But religious talk does not help if you don’t have the *will to live* inside you. When a person has the will to live he adheres to medication. Many, however, say, ‘I will die anyway,’ and return to their vices and street life. I don’t see things this way.”

Luis spoke of a new economy of life instincts organized around AIDS drugs. 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.”

Luis is indeed the representative of a new medical collective, and his discourse conveys present-day forms and limits of society and state: “I have nothing to do with society,” he says. “From my perspective, society is a set of masters deciding what risk is, and what is bad for them. I have never participated in that. As for the government, I must say that I am thankful for the medication. This is the good aspect of the state. The rest is for me to do.”

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Valquirene, 1997.
Photo: Torben Eskerod

“I Have No Fear of Living”

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

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

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

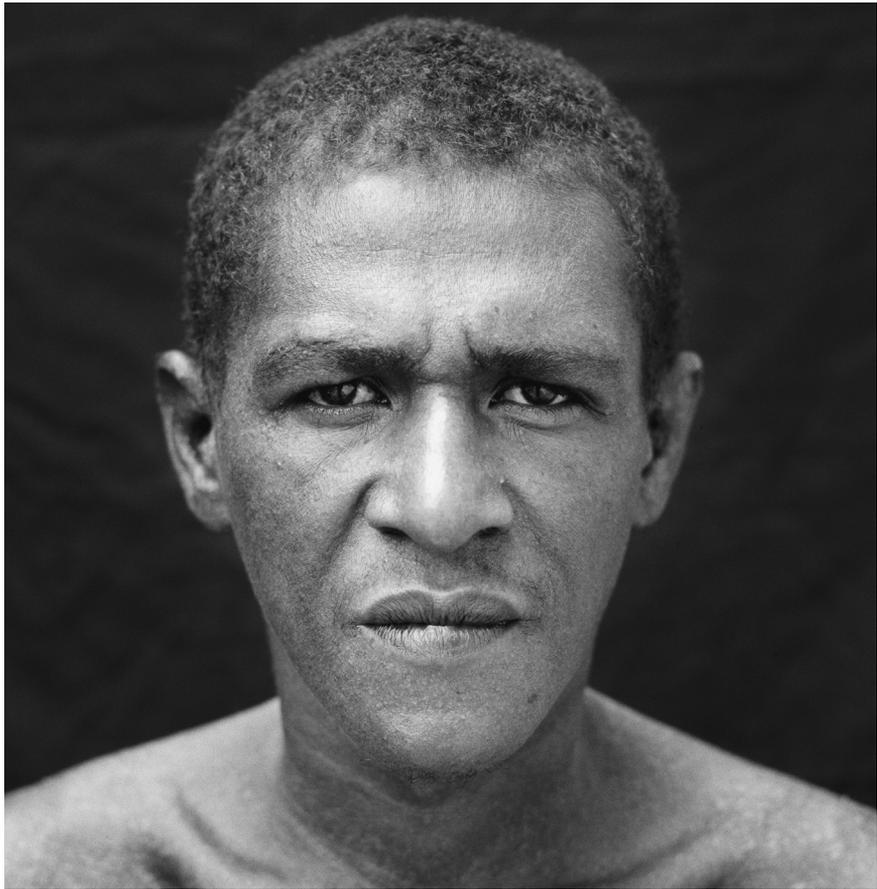
With the new therapies, she says, “I have no fear of living. I am only afraid of dying because of my son. I want him to study, to be a great man—then I can die.” Valquirene was learning to do handicrafts to maintain herself and planned to study computing. “These days, you need the English language.”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

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

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

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Evangivaldo, 1997.
Photo: Torben Eskerod

“It Is the Financial Part of Life That Tortures Me”

Will to Live

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

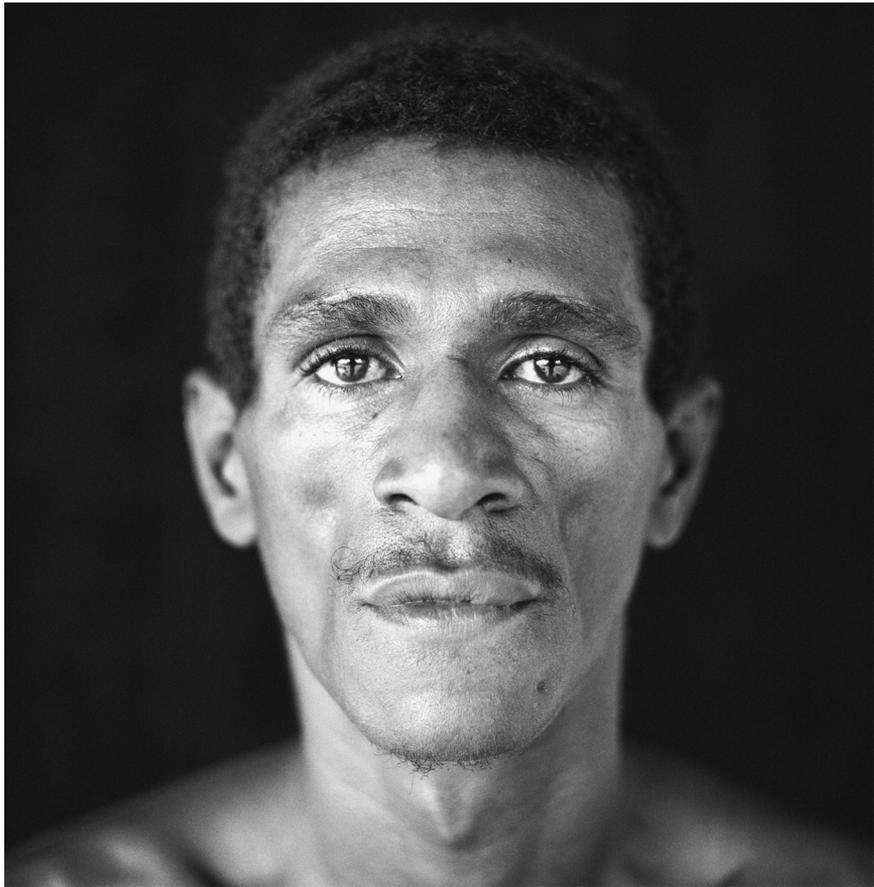
A former street inhabitant, Evangivaldo had been treated at the AIDS unit of the state hospital. Despite his extremely contagious, crusted Norwegian scabies, a social worker had sent him to Caasah with a “satisfactory discharge.” Itches and scabies soon spread throughout Caasah. Healthier residents had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

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

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

“Later, my work was to take prostitutes to the ships that docked here. An Italian man once gave me gifts. Women were never so tender to me. I am sure he did not infect me. I felt this desire—how can I say it?—it was love. He told me of those landscapes he had seen. He never returned. Now I think that had I traveled away, none of this would have happened; rather, other novelties.”

Public Culture



Evangivaldo, 2001.
Photo: Torben Eskerod

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

For the past three days we had tried in vain to reach him. We had a wrong address and no telephone. “I already had to move four times, because people discovered that Fatima and I have AIDS.” The couple had met at Caasah and now had a two-year-old daughter. Juliana was born HIV positive, but after eighteen months her HIV status changed. “She is healthy now. . . . A child is what I wanted most in life. Juliana fulfilled my desire, a dream I had. I thought I would die without being a father, but now I have a fruit of the earth.” We were happy to help him out so that he could provide for his family. “It is the financial part of life that tortures me,” he said.

We sat under a tree in Caasah’s backyard, and Evangivaldo looked at his 1997 photograph: “This work was important to me, it marked my history. Then I thought that I would not live. So many of those who thought they were the big guys of Caasah are already dead. My politics is to see things humanly. The one who is strong now must help the weaker. I close my heart when people call me *aidético* [a person with AIDS] and keep riding my bike.”

After a few shots, Torben told Evangivaldo, “You are a natural.” Evangivaldo smiled and said that he would show the portrait to his doctor and nurses at the hospital where he picks up his medication. Evangivaldo then showed us a piece of paper in which he had listed how his income was allocated and the debts he had to pay. I will never forget the force of his words and numbers, what he goes through in life:

I owe 75 *reais* to the pharmacist. I get 200 *reais* from disability. I pay 120 *reais* for rent. Electricity takes 20 *reais*. I also now owe 30 *reais* at the grocery store. We are trying to get Fatima a disability pension too. I am a Brazilian citizen. I walk with my head up in my country. I am not ashamed of putting my hands into garbage to pick up what I need. Those who rob should be put in shackles, not us. When Fatima cannot do the work, I am the man and woman of the house. Sometimes I wake up at 4 a.m., leave everything ready, and ride my bike for two hours, to get downtown. I go door to door, asking for a job. . . . There are days when I cannot get the money we need and I panic. My head spins, and I fall down. I hide in a corner and cry. Then I don’t know where I am. You cannot imagine how painful this is. But I tell myself, “Focus, Evangivaldo, you will find your bike and your way home.” And do you know why I manage to do this? It is because my daughter is waiting for me at home.



Nerivaldo, 1997.
Photo: Torben Eskerod

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

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

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

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

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

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

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

Physicians of Themselves and Their Worlds

Caasah's former residents are the new people of AIDS. After experiencing familial disarticulation and social abandonment, they have come into contact with the foundational experiences of Caasah and biotechnology. They empirically transcended their destinies. Now using AIDS drugs and on their own, these patient citizens face the daily challenge of translating medical investments into social capital and wage-earning power. At every turn, they must consider the next step to be taken to guarantee survival. Back in the world, they refuse the position of leftovers and break open new trajectories. Life is in transit. They humanize technology and redo themselves in familiar terms. The unwanted transform themselves into objects of desire, punctuating the world with medical signifiers. And throughout these medical trajectories—a second nature of sorts—they actualize the dignity and hope that had hitherto been virtual to them.

Yet this is not an inclusive form of care or citizenship. Many are left out, saddled with other kinds of categorizations, such as drug addict, prostitute, beggar, and thief. Burdened by these labels, it is difficult for individuals to self-identify or to be identified as AIDS victims deserving of treatment and capable of adherence. To get that to which they are legally entitled, these individuals must not only identify themselves as belonging to the class of those served but also constantly seek out services. To retain services, furthermore, they must behave in certain ways. As a result, they largely remain part of the underground economy and a hidden AIDS epidemic.

An ethnographic analysis of these linkages between AIDS drugs and care (or the lack thereof) broadens our understanding of what determines health outcomes among the most vulnerable and of the forms that AIDS is taking. It concomitantly underscores the everyday practices that separate inclusion from exclusion. As life extension is now also possible for those who have been historically neglected, ethnography charts the trajectories that determine this mobilization. By noticing and documenting this micropolitics of survival, ethnography illuminates the paths through which people become the physicians of themselves and of their worlds amid the growing tension between health as a public and a private good.