Part 4

Responses from Civil Society: Latin America and Asia

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From Global to Local and Back to Global: The Articulation of Politics, Knowledge and Assistance in Brazilian Responses to AIDS

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Introduction[1]

Brazil is regarded worldwide as an example of a successful and articulated response to the AIDS epidemic. Investing in prevention and assistance, civil society and government are engaged together in efforts towards reducing the number of new infections and the death rate. In the year 2000 the number of people infected with HIV in Brazil was estimated at 600 000 – about a half the 1 200 000 earlier projected by the World Bank for the country.[2] The number of people receiving antiretroviral therapies keeps increasing; by September 2005 about 170 000 people were receiving treatment, with an overall 75 per cent adherence.[3] Brazilian expertise on AIDS is now exported to different world settings, including Asia, Africa, Eastern Europe.

What are the reasons behind this apparent success? Recent discussions have emphasized two major factors: the power of an organized civil society (see also Chapter 14) and the ability to produce and distribute antivirals in the public system. That ability counted on several elements: political will to provide medicines free of charge within the public system, technical ability to produce the medicines in national laboratories, political ability to subvert the rules imposed by big pharmaceutical companies and trade organizations regarding patented formulae, and creativity to replicate the formulae via reverse engineering.

This model is accurate, yet oversimplified; attempts to export it to other situations may lead to the reification of its components, to artificial investment in single factors and to predictable failure. While there is general enthusiasm over Brazil's experience, AIDS scholars have critically analysed some of the problems involved with the possibility of replicating it elsewhere (Berkman et al. 2005).

In this chapter I will contribute to the discussion by historicizing the organized response to AIDS in Brazil. I will show how the articulation of local

action and global flows in funding and expertise created a unique situation, one that shaped the actual local responses and turned the conflicting and scattered scenario of 1980s Brazil into the joint platform of action that, from the mid-1990s on, allowed for the development of an exemplary national AIDS programme.

Short retrospective of a change

Things have changed since the time I first approached Brazil's responses to AIDS in the early 1990s.[4] Many of the activists, physicians, public health specialists, epidemiologists and social scientists that I met back then, struggling with difficulties and inventing creative responses to overcome an anxious present and a jeopardized future, ten years later became successful consultants for a variety of countries in Africa, Asia, Eastern Europe, and international agencies. From just another response to a global crisis, Brazil became a global exporter of response expertise. Time and again, in international meetings, we can find delegates from different places asking Brazilian delegates for guidelines. Particularly since 2001, Brazil has been regarded by policy makers, AIDS activists, physicians around the world and the leading health organizations as the best example of a successful response to AIDS.[5]

Not fully a part of the inner circle of developed countries, Brazil appears as proof that there are ways of curbing the epidemic, proving wrong the grim predictions hanging over the developing countries. India and China, aware of dire predictions regarding the expansion of AIDS in their population, and often depicted as potential 'new Africas' in terms of future infections rates, have people who work on the possibility of learning, borrowing or importing expertise from the Brazilian experience.

What can explain this shift in Brazil's position in the global context of responses to AIDS?

World fractures, before and after the 'cocktail'

Ever since the announcement, back in 1996 at the International Conference on AIDS held in Vancouver, Canada, of the effective anti-HIV treatments, the world tends to split between those who are able to reach, purchase, and use those treatments, making AIDS a somehow manageable disease, in spite of its costs, and those who, unable to pay for the new treatments, will remain under the collective and individual stresses of the devastating epidemic.

This fracture is well known in world health patterns; it resonates the split between the 'developed' and the 'developing' or, as it is more popularly used in Brazil, between 'first' and 'third world', or still, in some political lingo, the 'North' and the 'South'. Hardly anyone takes literally the geographical references of this partition, as it is a matter of economics and politics rather than of space. And yet the distinction remains stable and convenient, sometimes

overlapping with geography, sometimes referring to exceptions to that tendency, such as the 'first world within' the developing countries and the 'third world within' the developed nations.

During its first decade, the AIDS epidemic short-circuited that partition. AIDS potentially affected everyone, whether or not they had the means to pay for treatment; treatments were just not there.[6] Nor was there enough accumulated knowledge that could be readily capitalized into the development of new drugs, even if there had been enough attention and funding. For a few years AIDS remained a leveller that killed rich and poor, left and right.

For those who had been surrounded by preventable yet prevailing endemic diseases like malaria, tuberculosis, malaria, pneumonias and gastro-intestinal disorders, AIDS came as another disruption and another terrible disease in a too well-known scenario, unbeatable by treatments that were unaffordable to begin with. But for those who were living in sanitized environments, using informed behaviour to avoid ailments, doing their best and paying their most to keep illness at bay, a new incurable disease appeared as a galvanizing shock. It was first compared to cancer (the 'gay cancer') in its unpredictability and means to defeat modern medicine. But when AIDS became known as an infectious disease, indignation arose even more among those not used to that sort of vulnerability. How could a 'mere' infection, in spite of its complexities, not be handled by modern medicine? Was it the politicians that prevented it selectively, as many in the US thought for a while? Was it homophobia? Racism? Fear of different lifestyles? Neglect for the populations at risk?

A first wave of activism developed to supply what seemed to be missing: by fund and awareness raising, it tried to promote public acknowledgement, intense research, rapid solutions, treatments and drugs – a cure. The rationale was, with more money and less red tape, more awareness and less denial, a cure should come faster out of the medical research labs. Things turned out to be slower and more complex. It took years, and many lives, before anything palpable made a real difference in treatment. Yet, something else 'less palpable' developed within that context.

The activism that grew at the time created a new sort of social movement with a major influence in global health politics. It is interesting to note that while most of the world reacted to AIDS with assorted forms of denial, with a 'not us', 'not here', and 'no such thing exists', as it lingered for too long in some places,[7] it was a niche of parochially oriented politics within the gay communities in the richer cities of the western world[8] that developed a sort of awareness and activism that ended influencing global politics.

In the second half of the 1980s some of the energy of the early AIDS activism had affected global agencies like the WHO and a few major donor NGOs. It was a time when activism moved faster than biomedical research. There were still no appropriate medicines available, but there were intense developments in prevention, awareness, and stigma-reduction. There was

global action, transnational efforts, cooperation, new sorts of connections, bridge-building; humbleness and empathy went hand in hand with creative anger and radical movements. For many, it was an entirely new world of awareness, emotions and politics. At moments, it seemed as though all health politics on earth were going to change. Talk of empowerment, gender, sex, oppression, prevention, commerce and education, became as familiar in AIDS conferences as reports of clinical trials and laboratory research were. What public health specialists around the world had been preaching for decades – bring the social into the medical, or, health *is* politics – was now nearly commonsense in the AIDS front.

In 1996, after years of trial, fighting, and error, too late for many, right on time for many others, the news of an efficient therapy finally broke out. On time for many, but, in fact, only for some; precisely for those who had most expressed their indignation with the fact that their lives had been under threat due to the lack of medical knowledge on how to handle this infection. For that fraction of humankind, after 1996, things seemed on their way to be under control; that was the fraction that was more familiar with, and could afford to access, the powers of medical knowledge.

For most others, whether thought of as in the wrong side of the world, of power, and of economics, things remained, as usual, out of reach. As it happened for parasitic infections and for lung bacterial infections, there might well be an efficient treatment somewhere, but not right there, not in one's reach. Coughing, wasting, burning with fever, what was there radically new with AIDS that might not be known before?

At this point, the question is whether the pattern of a dual health system in a fractured world re-emerged with the announcement and use of effective AIDS treatments after 1996. Evidence supports a *yes*, but only partially so. The lack of knowledge and means to treat AIDS, previously shared by rich and poor alike, was replaced by scarce commodities and valuable knowledge. None of them being free, available at a high cost, they re-introduced the differentiation that had been temporarily suspended. The frenzy moments experienced at International AIDS Conferences, with all different world representatives together working towards a common goal, gave place to the routine of a world with commodities and prices, a world whose citizens are consumers and the non-consumers are excluded.

There must be an emphasis on the exorbitant price consumers are paying for their product, which can amount to tens of thousands of dollar per person annually. It is not just the prime matter and the manufacturing process that they are paying for, it is the embedded cost of privately owned knowledge. Pharmaceutical companies' royalties include the costs of research, showing how a pill is also the sum of an endless chain of operations, cognitive, legal, chemical, intellectual, manual.

And yet things did not go back to where they were before the global efforts to fight AIDS that arose in the late 1980s and early 1990s. There were

undeletable marks everywhere: the global consciousness about the pandemic, the engagement of multiple sectors of the society, and the need to use complex, multilayered models of understanding, where the social dimensions are a mandatory element within the main frame. And that is when, where, and why, Brazil comes to play a particular and highly visible role.

Escaping predicaments in Brazil

While the grim predictions about the course of the epidemic remained at the front, with relief for the few who could pay the costs of treatment and delayed hope for the many who could not, unexpected good news came from Brazil. Curbing the epidemic, alleviating collective stresses and making treatments available for those who need it, Brazil came as the much quoted example. How did this happen?

This is the question that people from everywhere put to those who have been involved with, or close to, Brazilian AIDS politics. In academic circles in the United States I would witness directly that kind of interest about AIDS in Brazil. In one event at a major university, delegates from India and China asked for Brazil's inspiration in order to model their own countries' responses to AIDS.[9] Brazil was represented by no ordinary delegate, but by the very President who had been in office when the crucial decisions were made, Fernando Henrique Cardoso, together with his wife, anthropologist Ruth Cardoso, involved with AIDS-related programmes during her time in Brasília.

When asked about the reasons for Brazil's apparent success, President Cardoso tried not to single out the role of his office, acknowledging that his successor President Lula da Silva followed the same policies. Rather than the former president, it was as a sociologist that he provided an answer emphasizing the fact that Brazil had a strong civil society. That was, in his words, the crucial factor behind the success of an original policy. That policy included medication policies, attitudes towards patent rights and policies of knowledge, international negotiations with the World Trade Organization, and a high public investment in health.

The answer was not about the efficiency of medicines, nor a display of figures and tables illustrating success rates. Neither was it one of epidemiological graphics, or a speech about individual agency, singling out heroic actions or political decisions. Nor was it a chronological list of key events. He offered instead a synthetic and valid sociological explanation. But, as other explanations, it has its limitations. In the following sections I will discuss some of its difficulties and suggest how we might introduce some complexity into the explanation.

It is true that Brazil has a very strong movement and motivated AIDS constituency, or, in other words, a strong and organized 'civil society'. That accounts for people directly affected by AIDS either by being sick, infected,

vulnerable, by feeling powerless to cure or to distribute means for treatment. It includes people who were widowed, orphaned, in loss, anger, solidarity, or simply touched by the general impact of a major epidemic. That movement's main component corresponds to the AIDS NGOs that developed in the country, particularly, but not exclusively, in the cities of São Paulo and Rio de Janeiro.

But this movement had not been there forever, nor even for too long. In the late 1980s and early 1990s, when Brazil was not yet a positive example for international AIDS news but was rather seen as a source of preoccupation for international agencies as a site where the epidemic might grow rapidly, local 'civil society' as we know it today was still in the making. The nation had just re-emerged from a dictatorship that would not support civil rights. In many senses, the social movement originated in the struggle against the dictatorship, benefiting from a wider international support for humanitarian causes, development and civil rights. Community associations were influenced by different streams, including the sectors of the Catholic church and international funding for development (e.g. Ford Foundation) and towards the reduction of social affliction (e.g. Norwegian Red Cross). As some analysts have shown, the very word 'Non-Governmental Organization' (NGO) arose from northern funding and support to the fight against authoritarian regimes in Latin America (Landim 1988). One of the reasons evoked was that there was no strong civil society in Brazil and that it needed to be strengthened as a means to overcome under-development.

Apparently, the funding of local NGOs by development agencies had a rapid positive outcome. At the outburst of the AIDS epidemic, there was enough strength among the Brazilian NGO sector to grow rapidly and intervene; AIDS was one major catalyst of the sector. On top of that, the AIDS movement recruited a sort of radical energy that transcended the fight for individual rights as practised in the US. In a sense, the AIDS movement in Brazil was more universal oriented than its US counterpart. While New York AIDS activists fought for immediate results and requested action from their representatives via letters and faxes, Brazilian activists set out for wider goals and took on more radical stances, while having shorter expectations of immediate influence. They acted against an inherited authoritarian state that for decades had done nothing for the population but repress it. In the beginning, the government was, by definition, the enemy. Only much later did that sort of energy affect the government as well.

AIDS, knowledge and politics

In my first approach to the Brazilian experience my interest focused on the production and use of medical knowledge. I aimed at understanding the role of Brazil in the global processes of knowledge making in a world of fractures and inequities.

In the early years of the epidemic in the US the blatant scarcity of knowledge made every little bit and piece of information matter. Whether this referred to a detail of the HIV genome, a folk drug reported to work, a tonic, coming out of a mainstream laboratory or from the new age repertoire, from spontaneous clinical trials with existing drugs or from exotic traditions of old Chinese medicine or African healers, all knowledge was important and circulated rapidly. For those whose lives were at stake – a large number in New York city alone – every bit of new knowledge was crucial, anything counted, and anything took easily a life of its own, beyond the plot of research it was embedded in. One could talk on the streets about the most sophisticated details of high-tech genetic research and on the lab benches one could be found talking about the wildest ideas about cannibalism, orgies and blood rituals as the origin of AIDS. Bits and pieces circulated with meanings attached and invested. My interest covered the entire variety of knowledge flows, which included scientific knowledge, clinical knowledge, practical knowledge, organizing knowledge, activism, ways of coping, and many other sorts of knowledge. While I tried to keep up with them all, as they affected one another, I had a main interest in the dynamics of production of hard-core biomedical knowledge. Biomedical research was a piece among a wider variety of circulating knowledge – yet not just another piece like any other, but one around which many others evolved and shaped.

HIV had recently been named and described as a new entity. It was not uncontested. The field allowed for dissention and variety. This should not be surprising to anyone familiar with the history of medical knowledge, as consensus is never achieved rapidly. The history of other infectious diseases has shown that it may take a long time before scientists agree on what should be taken as etiology, modes of transmission, not to speak of consensus about treatment, prevention or public health measures. But while this is familiar to historians and students of science, it appeared disturbingly confusing in the context of the exposure of the process of production of knowledge about AIDS. The sense of emergency surrounding AIDS exposed the slow road to consensus achievement. Rarely, if ever, was there so much direct scrutiny over what was going on in science labs.

Besides being visible, what else was new regarding the process of producing knowledge, or consensus achieving, in the field of AIDS? One thing stood out: that the constituencies, or at least its more vocal segment, the politicized gay groups in North American cities, directly influenced research. At a first stage, constituencies asked for research to be done, to be done fast, and to be done efficiently. They helped scientists by raising funds and providing volunteers for trials. At a second stage, the growth of treatment activism created a sophisticated form of influence; activists studied and mapped the field in order to signal specific lines of research that were uncovered, or some that were wasting time by repeating others. They formulated new questions. They provided their own body tissues and cells for research, participated in

clinical trials, and suggested creative venues of exploring the immune system, immune reactions, AIDS related infections, HIV infection, HIV itself, HIV specific treatments, or treatments directed to some components of HIV. This happened particularly in the early 1990s, and some of the antiretrovirals that would later become part of the consensus therapy, announced in 1996, were part of those discussions. Compared to epidemics of the past, things were indeed fast; and yet they were too slow for the urgency of the many that had their lives on hold.

There were attempts to document and theorize this interaction, along the lines of what had been done a decade earlier regarding the impact of women's movement on health. It was about the constituency influencing the production of knowledge at instances, of politics helping define some of the choices that are made in the process of research and the making of new knowledge, as Steve Epstein so thoroughly analysed (1996).

But the question was not just about empowered constituencies who could fight for their rights and had almost immediate impact on the AIDS research policies followed in the US and northern Europe. AIDS affected the entire world and, for moments at least, it appeared that global action was promoted: the WHO, followed by the creation of UNAIDS and the joint efforts of international agencies, national governments and private foundations, promoted a sort of action that involved the entire world at once. Or so it seemed. What would that mean in terms of knowledge production and circulation? What would be the role of those who had always been familiar to infectious diseases, to epidemics, to the complex presence of social dimensions at the very forefront of health, suffering and health care?

Or, in other words, what was the role of the developing world in the production of an understanding of the global epidemic? How could we describe it along the lines of an understanding of how knowledge is made, consensus is achieved, adopted, imported, exported? Would there be dissent, as later happened with some African leaders, or, instead, unrestrained acceptance, or a promoted critical discussion in what mattered the most?

The mainly gay AIDS constituencies in northern countries, as had happened with the women's movement two decades before, were able to point out some of their needs and some of the lines along which research should be promoted. Would the Third World countries be able to make the case for the need to develop low cost treatments, effective prevention models, potential synergies with prevalent diseases, infectious co-factors, specific pathologies, and bring their own experience with infectious disease into the mainstream research?

One thing seemed obvious to me: that Third World scientists were far more acquainted with infectious diseases than their US peers. While 'tropical medicine' had nearly disappeared in the 'North' by the eve of AIDS, it was alive and flourishing in southern countries. How would that shape into the

possibility of producing a meaningful input into the global knowledge about AIDS?

Brazil in the world system

That hypothesis brought me to Brazil in 1990. AZT had just been out, but its effects were limited and its cost was high. There was no cure for AIDS. HIV's genome was being worked. There was still much to learn. It was not yet clear to everyone what should be the leading way to develop adequate responses to the new epidemic and the many infections related to it. In a country that had always kept the scientific and medical specialty in infectious diseases (DIP – Doenças Infecciosas e Parasitárias), how did the new epidemic fit? What were its links to other infections, to prevailing poverty and its health correlates, to the fracture between rich and poor, the first and third world within? How would that be approached in the clinic, in the media, in the public policies? Was the accumulated knowledge regarding infectious diseases of any use, or did AIDS appear as something entirely different? Would there be any connection between the previous work and research by local scientists, clinicians, constituencies and the new demands of the AIDS epidemic? Would there be any impact of local developments in the global scenario?

While conducting fieldwork, I could find plenty of potential contributions to flow from local to global, from South to North; some of them were defined at the core models for the understanding of immunological diseases. But in the daily life of working with AIDS, the needs of the clinic, the urgency of treating efficiently, and the specific requests to make a research idea into a viable research project, shrank Brazilian biomedical creativity into a timid position; physicians would rather follow what came out in the press than venture hypotheses based on clinical experience, and researchers were, at best, partners in international research projects, as I have discussed in detail elsewhere (Bastos 1999). At the time they placed themselves at the periphery of the science-making world, and they could not aim at providing the elements for a major shift in the global understanding of AIDS. Most of what turned into consensus was being framed elsewhere and imported. What they could do was to provide the best clinical assistance as long as there were the means for it; there were indeed a few exceptional settings where this happened. They could think and hope for affordable remedies but they could not create them and send them to the world. They could also engage in clinical trials or epidemiological research. Even though they provided a breakthrough view in some stances, like a first-hand understanding of the link between contemporary TB and HIV, they did not fully take it as a major contribution that inverted the usual core–periphery distribution of knowledge.

Among the Brazilian social sciences and AIDS NGOs I found a different atmosphere than that of biomedical settings. It happened as if the NGO connections with mainstream centres like the WHO and Northern funding

agencies followed different routes and rules than those of the biomedical community. Different agendas and different paces.

At that time, the leadership of the AIDS programme at the WHO was engaged in listening to worldwide constituencies as the only way to develop efficient AIDS policies. With no chemical cure in sight, *prevention* was the word, and prevention was to be implemented by community organizations if it was to be implemented at all. In that sense, the flows between the main central agencies and the NGOs I visited in Brazil happened both ways. In contrast to what happened within the core of biomedical sciences, the creative responses developed by social activists in Brazil came rapidly to the top levels of global institutions and, from there, spread around the world. A good example comes from the formulations of Herbert Daniel,[10] a board member of the Brazilian Interdisciplinary AIDS Association (ABIA) and a founder of the Pela VIDDA group.[11] A writer and a political activist, Daniel published extensively in ABIA's newsletter and spoke out in many public places. His voice, together with Betinho's, another founder of ABIA whose life had been long involved with anti-dictatorship politics,[12] helped shaping a public awareness regarding AIDS as a political and social issue that affected everyone closely. The media had been treating AIDS as not only a gay and exotic disease but also as a foreign, northerner disease. The acknowledgement, by public figures, that AIDS was also their problem, and their insistence on the fact that it was anyone's problem, helped broaden its scope. Or, in other words, the idea that AIDS was a problem that affected society in general and that it should be addressed by public institutions started earlier in Brazil than in most other places.

The awareness-raising promoted by ABIA, in which Daniel had a major role, included a number of messages regarding prevention, sharing responsibilities, stigma-reduction, and the promotion of solidarity. The very words of Daniel were adopted by WHO. The first leader of its Global Programme, Jonathan Mann,[13] acknowledged the fact by making a public homage to Daniel in the 1992 International Conference held in Amsterdam and by dedicating to him the state-of-the-art book *AIDS in the World* (Mann et al. 1992).

In sum, the circulation of knowledge in the spheres of prevention and social action was intense and multi-directional, whereas its biomedical counterpart very much remained as the traditional, North–South colonial style that accounted for no meaningful South–North contribution except when – like under colonialism – they were about prime matters and raw data.

Interconnections

Why were these two spheres so different? If we imagine a densely connected world, as theorizers of globalization like to suggest, actual networks emerge with different densities, both due to their particular qualities and to

historical contingencies. For instance, the leadership of Jonathan Mann at the Global Programme created a difference in attitude and in the promotion of community-based organizations as partners in the struggle to contain AIDS. Whether street sex workers, religious agents or gay activists, their voices were crucial in understanding, reacting and acting upon the epidemic. Knowledge flowed in different directions, back and forth, shortening and inverting hierarchies. Nothing of the sort happened in the high-tech world of contemporary biomedicine, even though there might have been a lot to learn from the wards of the most remote and peripheral hospitals.

While in the field I got a sense that the networks of biomedicine and the networks of social action, the latter intimate to the social sciences (for many of the NGO leaders were social scientists), were quite independent in spite of sharing the same wider goal. At least this was my experience in Rio de Janeiro in the early 1990s. Even though major NGOs such as ABIA had been created with the participation of physicians and biomedical researchers, there seemed to be little communication between them and social activists. One the one hand, activists regarded health services as part of the government sphere, prone to the same rationale that they were confronting by definition. Individual physicians might be good partners in a common struggle, but the biomedical establishment was on the side of the government, and whatever the government was doing was inadequate. On the other hand, AIDS physicians regarded activists as complainers that were not always fair on their targets, unable to address the true difficulties of treating AIDS, lost in rhetoric about human rights and condoms, and incapable of fighting for the basic health needs that the populations with AIDS would require.

The spheres were, then, apart. The interaction between biomedicine and social organizations, as I had known it before in New York city, via the world of 'treatment activism', did not develop in Brazil until the mid-1990s. And even then it was as a response to attempts to implement vaccine trials seen with mistrust in a country accustomed to reacting against potentially damaging experiences from pharmaceutical companies.[14]

By the time I left Brazil and wrote *Global responses*, in the mid-1990s, my expectations regarding the Brazilian impact on the global making of knowledge in response to AIDS had not been matched. I could report no spectacular influence in change, parallel to what is described for the impact of northern gay-based activism in the world of biomedical research. I had to refrain from theorizing about new trends in global interaction and about new ways of knowledge making. If in the sphere of activism one could find an intense circulation of knowledge throughout the entire world, in several directions, at the core of biomedicine the interactions followed a pattern of core–periphery distribution of knowledge. Whatever might be new and meaningful came from the first world. That also meant that if a cure for AIDS was to be found, it was likely to be first-world style, therefore expensive and prone to replicate the divide between rich and poor that had been there before.

Change

But things changed. Things started changing after the 1996 announcement of the effectiveness of a combination of antivirals at the Vancouver International conference on AIDS. Like AZT before them, the combination of new drugs was expected to be expensive. The optimal therapy consisted of a succession of antiviral 'cocktails', each of their components at a prohibitive cost. Neither the prime matters nor the manufacturing process made them that expensive; it was the less tangible payment for patented knowledge that accounted for their price. The pharmaceutical companies that developed the drugs demanded returns from the expenses with the research involved in the development of those formulae. A major partner in the health industry and a crucial element in the development of new treatments, pharmaceutical companies do not necessarily abide to a logic of serving the public by maximizing health and well being; theirs is the corporate logic of maximizing profit.[15]

It was at this moment that Brazil took an innovative stance within the complex web of medical care, justice, knowledge, trade rights and human rights brought together by the AIDS epidemic. After years of fighting for the end of AIDS, now there were treatments that might, at least, put an end to many of the ailments experienced by people with AIDS. Both the clinical and the serological evaluation of the effects of the new treatments were highly encouraging. People felt much better and HIV seemed to go undetectable in their blood. The new drugs were the closest there was to a cure. Yet they were too expensive, and the main reason behind it was the embedded cost of knowledge. Like in older times when pharmacists charged their clients for the use of family recipes kept in secret, companies were charging for the use of 'secret', or patented, knowledge – but now at exorbitant prices. According to international rules of trade, companies and subjects are entitled to charge for the use of any piece of knowledge they 'own'.[16] But 'owning' and charging for knowledge that is life saving, particularly at a time when so much pressure had been mounting to make available any piece of knowledge that could intervene on the AIDS epidemic, incurred an immoral resonance. Around the world, companies were criticized for the prices charged and were pressed into making them available for less cost and more people.

Brazil was able to short-circuit the problem and make those expensive drugs available for free in the public system. How did it happen? Within the limits of this article we can only outline the factors that contributed to that 'success story'.

a) The public health system

In spite of being so poorly endowed, the system existed and guaranteed assistance to anyone. As it depended on public funding and often went through periods of intense deprivation, whoever could afford private care sought it

elsewhere, leaving the public system for the poor and the disenfranchised. However, the public system provided high quality care on occasions, such as within the public University Hospitals, where the better equipment and prestigious medical faculty could be found. In Brazil, unlike the United States, public universities are in the highest ranks of educational prestige, and their hospitals are accordingly equipped and praised. Assistance involving expensive procedures and sophisticated techniques was more readily found within those settings than in the private sector. Eventually, some sectors of the university hospitals worked with special grants and partnerships that provided the most sophisticated equipment and brought together the most distinguished researchers. Under those circumstances, the public sector was the place where most action upon AIDS took place.

b) The specialty of infectious diseases

AIDS was allocated to the specialty of Infectious Diseases in the early years of the epidemic. That specialty was almost entirely based on the public system. Its clients were mostly the poorer populations, affected by endemic and epidemic diseases, from which the groups with higher living standards were more protected. Health practitioners involved with the specialty had, more often than in others, a strong sense of social commitment.

c) The development of a mature, multi-actor AIDS culture

If the different sectors involved in the response to the AIDS epidemic in Brazil, like the NGOs, the health services, and the government, were seemingly disconnected in the 1980s, showing different agendas and different connections to the wider world, by the mid-1990s they had developed strong links and converging agendas – something that was not unconnected to the fact that a major loan from the World Bank required coordinated action (Biehl 2004, Foller 2005).

The existence of a tangible goal like the antiviral therapies automatically created a common agenda for the different sectors. After years of raising public awareness regarding the need to develop an effective response to AIDS, there was something clearly identified to fight for: the new, albeit expensive, antiretroviral therapies.

d) The law

Brazilian constitution grants protection to its citizens. Under that principle, AIDS advocates developed suits against the government for not providing adequate treatment to people in need – people who were HIV infected and sick and were not given the existing treatments. Some of those law suits were a success (Scheffer et al. 2005) and created a precedent to the general distribution of the antiretrovirals in the public system. None of this would

have been possible if it were not for the accumulated history of awareness raising and bridge-building between the different sectors.

e) The know-how

Biomedical research has had an important role in the history of Brazilian nation-building, and much of it was associated with the development of self-sufficient laboratories, with a local pharmaceutical industry and with the development of knowledge about infectious diseases. With the combination of that history, sophisticated laboratories, pharmaceutical know-how and a commitment to social causes, Brazilian scientists were able to replicate, via reverse engineering, the formulas of some of the antiretroviral treatments that made a difference for people with AIDS. That ability gave Brazil an increased power of negotiation regarding patented knowledge.

f) Power of negotiation

Brazilian government had too easily signed WTO TRIPS (trade-related aspects of intellectual property rights), tying the country to the payment of royalties that included regarding those related to AIDS drugs. However, the mounting pressure from what was already an organized civil society, with a common agenda of responding to AIDS and using all possible means to be successful in the task, lead to an arm-bending situation with international pharmaceutical companies. Brazil threatened to break the prevailing patent rules and manufacture the drugs in the country if the pharmaceutical companies did not drastically reduce the price charges for the anti-retroviral drugs.

This sort of arm-bending would not be possible if it were not for Brazil's particular history and insertion within the Americas – combining, at once, the full entrance in neoliberal economy and an older tradition of struggling against what were seen as northern imperialist rules and regulations.

Conclusion

The synergistic combination of the factors described above may depict how, at a precise historical moment, Brazil was able to provide an exemplary response to the AIDS epidemic. No single factor accounts for this unique response – it is the outcome of a combination of forces, events and singularities. The amount of energy developed within the activists' sphere was reinforced by the international agencies and became strong enough, after a few years, to 'infect' the government to act in the same sort of style – the 'activist state' that President Cardoso sometimes refers to (Biehl 2005: 115). NGOs recruited the government for their cause and the government recruited the NGOs for their intervention in the public sector. A synergy resulted in action of a kind that inspired the world.

Notes

1. This paper was presented at the conference *The Politics of AIDS: Globalization and Civil Society*, jointly promoted by the Göteborg University and the Museum of World Culture, 18–19 May 2006. I am very thankful to Maj-Lis Follér and Håkan Thörn for the invitation and for the useful comments that emerged at the discussion. Final editing for this paper was done while Visiting Faculty at the Watson Institute for International Studies and the Department of Portuguese and Brazilian Studies, Brown University, with a grant from the Luso-American Foundation for Development.
2. The "good news" should be contextualized: they mean there are fewer new cases than the worst projections; the number of new HIV infections per year has approximately stabilized, and actually slightly reduced for men – while the new cases among women have grown (http://www.aids.gov.br/).
3. http://www.unaids.org/en/Regions_Countries/Regions/LatinAmerica.asp.
4. I conducted fieldwork among AIDS workers in Rio de Janeiro between 1990 and 1992, preceded by a short exploratory trip in 1989 and completed by follow-up trips. This was initially part of the work towards a PhD thesis in anthropology at the City University of New York Graduate Center, later turned into the book *Global Responses to AIDS* (Bastos 1999), but became – as occasionally happens with fieldwork – a larger experience of involvement with the different communities of actors intervening in the local responses to the epidemic – activists, health workers, bench scientists and social scientists. I also worked as a news reporter covering the International AIDS Conferences for the Portuguese weekly *Expresso*.
5. In a chapter dedicated to civil society and AIDS in Brazil, Maj-Lis Follér (2005) analyses in detail the entanglement of local and global social actors involved in the Brazilian civil society responses to AIDS. Critically analysing the role of pharmaceutical corporations, in the process, João Biehl (2004) develops the concept of a new, treatment centred and pharmaceutically-bound biomedical citizenship and the new mechanisms of exclusion it carries along.
6. In New York city and California, at least, there were all sorts of exploratory uses of promising drugs, whether coming from traditional herbalist bodies of knowledge (like the Chinese cucumber) or from manufactured drugs available over the counter outside the US. In pre-internet times, solid networks of consumers developed to discuss the uses and availability of non-tested drugs that offered the slightest promise of benefit.
7. In South Africa that sort of reaction was endorsed by the government until the mid 2000s, to the dismay of AIDS activists there and anywhere.
8. The West and East of the early 1980s are about the cold war partition, which still structured much of the international scene at the time.
9. I would witness this interest at a conference at the Watson Institute for International Studies and the Portuguese and Brazilian Studies department, Brown University, fall 2004, re-stated two years later.
10. Herbert Daniel (1946–92), a political activist and an author of fiction and non-fiction books, was one of the most influential AIDS activists in Rio de Janeiro, in Brazil and in wider spheres. Parallel to the empowerment of People living with AIDS (PWAs) that developed in the northern hemisphere, Daniel fought for the political stance of refusing to accomplish the predicament of death in its many senses, "civil death" – or the erasure of political rights by a conservative and prejudiced society – being among them. He promoted solidarity as an answer to fight

fear and hopelessness and he had a major role in the early years of ABIA and Pela VIDDA. Among many articles and speeches, he wrote the booklets *A vida antes da morte*, and *A Terceira Epidemia*.

11. Pela VIDDA is an acronym whose initials mean "Pela Valorização, Integração e Dignidade do Doente de Aids" (for the valorization, integration, and dignification of the AIDS patient) and that stands for "For Life" (pela vida). It was founded in Rio de Janeiro in 1989, mostly due to the impulse of Herbert Daniel. After Pela VIDDA-RJ, many other similar groups developed in other Brazilian cities.
12. Betinho, or Herbert de Souza (1935–97), was the founder of both ABIA and of IBASE, an umbrella NGO that supported all different research and intervention projects in Rio de Janeiro. Betinho wrote extensively and was one of the most prominent voices of people with AIDS in Brazil. His articles include "O dia da cura"; " A AIDS não é mortal", "Direitos humanos e AIDS."
13. Jonathan Mann was the leading figure of the distinctive global action upon AIDS promoted initially by the WHO. A Public Health specialist with a close understanding of the complex entanglements of health and society in the developing world, particularly as experienced in Africa, Mann initiated and headed, from 1986 on, WHO's Special Programme on AIDS (later Global Programme on AIDS (GPA)). He promoted an innovative policy engaged in listening to the local constituencies and taking immediate action. He actually went around the world to assess the issues and defined invertention programmes accordingly. He included human rights issues in the frontline of AIDS action. The AIDS prorgramme became somehow too visible within WHO structures and in 1990 he resigned from the job claiming lack of support. He moved to the Harvard School of Public Health and started a new sort of influence from there – unhappily interrupted by his sudden death in 1998.
14. In the mid-1990s WHO and other agencies tried to implement joint projects with Brazilian research centres in order to develop extensive efficacy trials for vaccine prototypes that had passed security trials. The issue generated an extensive public discussion and one of the issues often raised was the need for caution regarding any attempts on the part of northern laboratories to use Third World bodies as guinea pigs for experimentation; this reaction, adopted by many Brazilian activists, contrasted sharply with the eagerness with which people with AIDS in the US volunteered to participate in clinical trials. While the latter expected their participation in clinical trials to improve their chances of getting closer to a treatment, the former had historical reasons to be cautious, due to occurrence of unsafe practices in the past. Overall, the vaccine trial issue gave rise to an expansion in the scope of topics discussed by Brazilian AIDS NGOs, from a purely social issues sphere to a wider understanding of the biomedical issues at stake.
15. AIDS activists were not shy to present pharmaceutical companies as guided by homicidal greed. A number of times they were targeted due to the prohibitive prices charged for certain drugs used for people with AIDS. This happened from early on in AIDS activism, before the "cocktail" of antiretrovirals. Targets included the companies that produced AZT, the first antiretroviral drug on the market, as well as manufacturers of drugs used in the treatment of specific opportunistic infections.
16. This is a problem that affects many other aspects of human life and the creation of inequalities. Any piece of knowledge can be patented and henceforth "owned", the "owner" being entitled to charge for its use even to those who may have used

it for centuries, as happens with the indigenous knowledge regarding therapeutic uses of plants.

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